

**A TALE OF ONE CITY – A HISTORY OF
HIV/AIDS POLICY-MAKING IN
EDINBURGH – 1982-1994**

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DECLARATION

This thesis has been composed entirely by myself,
and the research on which it is based is my own.

Helen Coyle

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LIST OF ABBREVIATIONS

ACMD	Advisory Council on the Misuse of Drugs
ACPO	Association of Chief of Police Officers
AIDS	Acquired Immune Deficiency Syndrome
APCG	AIDS Prevention Co-ordinating Group
ASG	AIDS Support Group
ATF	AIDS Task Force
BTS	Blood Transfusion Service
CAMO	Chief Administrative Medical Officer
CSA	Common Services Agency
CSO	Chief Scientist's Office
DES	Department of Education and Science
DHSS	Department of Health and Social Security
DTF	Drugs Task Force
EAGA	Expert Advisory Group on AIDS
EDAAG	Edinburgh Drug Abuse Action Group
EUL	Edinburgh University Library
GP	General Practitioner
GRID	Gay Related Immune Deficiency
GUM	Genito-Urinary Medicine
HEBS	Health Education Board for Scotland
HIV	Human Immuno-deficiency Virus
HTLV-III	Human T-cell Lymphotropic Virus-III
ID	Infectious Diseases

LAAG	Lothian AIDS Advisory Group
LAF	Lothian AIDS Forum
LAMC	Lothian Area Medical Committee
LAV	Lymphadenopathy-Associated Virus
LHB	Lothian Health Board
LHSA	Lothian Health Services Archive
LRC	Lothian Regional Council
NAS	National Archives of Scotland
RAG	Regional AIDS Group
RIE	Royal Infirmary of Edinburgh
SAM	Scottish AIDS Monitor
SCHIIDM	Scottish Advisory Committee on HTLV-III Infection and Intravenous Drug Misuse
SHEG	Scottish Health Education Group
SHEU	Scottish Health Education Unit
SHHD	Scottish Home and Health Department
SED	Scottish Education Department
SMMP	Simpson Memorial Maternity Pavilion
SPS	Scottish Prison Service
SRC	Strathclyde Regional Council
STDs	Sexually Transmitted Diseases
SWD	Social Work Department
VD	Venereal Disease
THT	Terrence Higgins Trust

ABSTRACT

The historiography surrounding the policy response to AIDS/HIV has largely focussed on the national or international picture. This thesis seeks to provide a much-needed local perspective by examining the dynamics of policy-making in Edinburgh – the so-called ‘AIDS Capital of Europe’ – during the period 1982-94. The thesis is primarily based on a wide range of hitherto unexplored primary sources generated by the Scottish Office and health authorities north of the Border. These sources have furnished new insights into the policy-making process and the interaction between the local and central state. In particular, it has enabled the author to compare and contrast the Edinburgh experience with that of other parts of the UK.

An introductory section locates the study within both the broader literature on the social response to disease and the more specific historiography of AIDS/HIV, while Chapter 2 provides a pre-AIDS history of the policy response to disease in Edinburgh. The main body of the thesis comprises four parts. The first two parts address the response to AIDS/HIV between 1982-1987, concentrating on the early role in policy-making of a medico-gay alliance, debates on the problem of haemophiliacs and AIDS as a ‘disease of the blood’, the increasing association of AIDS as a drug-related disease with associated debates on the uses of screening, needle exchange and methadone therapy, and health education. The last two parts analyse the policy responses between 1987-1994, especially the formulation of new care and treatment strategies, the relationship between voluntary and statutory groups and the establishment of a new health education campaign in Edinburgh.

While acknowledging that much of policy-making followed a UK pattern, the conclusion seeks to tease out what was distinctive about the experience of AIDS/HIV policy-making in Edinburgh, using specifically the findings of Professor Virginia Berridge as a comparator. The evidence would suggest that Edinburgh’s response to AIDS/HIV was shaped by local factors such as the legacy of previous responses to diseases, the distinctive drug-related epidemiology of HIV in the City, and the particular configuration of local pressure groups and civic authority. It was also heavily influenced by a number of distinctively Scottish factors, including Scotland’s legal and health education structures, its blood transfusion service and clinical input.

CHAPTER 1 – INTRODUCTION

Some time within the last two years a person visited Edinburgh and left the City with a sinister legacy. Who it was and where they came from will never be known. Except that it was a drug addict, carrying the AIDS virus, who shared a needle with one or other of the local addicts and, as a result, launched Edinburgh on its trail of notoriety as the second-highest centre of AIDS virus-infected drug addicts in the World.[*Edinburgh Evening News*, 10 January, 1986]

The first confirmed case of Acquired Immune Deficiency Syndrome (AIDS) in Edinburgh was identified in September 1984 at the City Hospital in Edinburgh. This was a terminally ill homosexual male, who had travelled up north and was already on the British register. Shortly afterwards, about twenty haemophiliacs developed Human T-cell Lymphotropic Virus-III (HTLV-III). However, by early 1986, three studies had confirmed a prevalence of HTLV-III amongst drug misusers in the City. One study showed that around 50% of those tested had become infected within the previous two years. Many of those found positive were women, some of whom had gone on to give birth to HTLV-III positive babies. While the potential for heterosexual spread had been acknowledged in connection with haemophiliacs, Edinburgh's high incidence of HTLV-III brought to the fore the potential for widescale spread of the virus throughout the United Kingdom, especially from those intravenous drug misusers who supported their habit from prostitution. Edinburgh's story informed debates on the uses of screening, needle exchange and methadone therapy and led to the formation of a Scottish Office Committee, whose findings and recommendations influenced the policy response not only in Edinburgh and Scotland, but across the rest of the UK, especially the introduction of pilot needle exchange schemes. By the 1990s, the policy response in Edinburgh had led to number of new

treatment and care strategies for AIDS sufferers and the establishment of a local education campaign, which emphasised the dangers of heterosexual spread.

Historiographical Context

This was a story not only shaped by the previous responses of society and governance to disease, but also part of a wider narrative of AIDS policy-making in the United Kingdom. Thus, in order to place this study in context, the first part of this chapter will examine three separate, but connected historiographies in relation to the social response to disease from 1800. The first historiographical piece focuses on the social response to a range of infectious diseases from 1800. The second concentrates more specifically on the social response to sexually transmitted diseases (STDs), whilst the third is concerned solely with the social response to AIDS. In doing so, a number of dominant historiographical concerns will become apparent. Foremost is the relationship between disease and society, especially the way in which perceptions of disease are often linked to wider fears and anxieties about morality. A second prominent concern is the relationship between disease and the state, particularly the manner in which health initiatives and policies are seen to reflect attempts by the state to control individual behaviour. A final recurrent strand in the literature concerns the relationship between disease and medicine; for example the way in which the medical response to disease reflects differences in medical ideologies, practices and treatment and is associated with the emergence of new specialities.

These historiographical overviews will be followed by an introductory section which describes the limitations of the existing AIDS literature, the aims of my thesis and the

sources that have been utilized. The chapter concludes with an outline of the methodology adopted and the structure of the thesis.

The Social Response to Disease from 1800

For some historians the social response to disease is a probe to gain insight into wider social issues and processes, such as social relations and social structures. For example, Morris's study of the British cholera epidemic in 1832 is designed to elucidate class and religious tensions.¹ Different perceptions of the threat of cholera are used to illuminate conflicts between the working, middle and upper classes, while differences in beliefs about the causes of disease reveal religious tensions, which are seen as an expression of wider anxieties about immorality. Similarly, in the hands of Rosenberg, the cholera epidemic in America during the nineteenth century becomes a means of viewing the prevailing cultural values within a society, particularly those of evangelical sects who believed disease was the result of sin.²

The relationship between the State and disease regulation, with respect to political regimes and health policy strategies, has also received much attention. Ackernecht was one of the first to explore this.³ He argued that there was a tendency for liberal nations to identify with an environmentalist understanding of disease and adopt an ethos of sanitation, while autocratic governments championed contagion theory and pursued interventionist quarantine practices. More recently, Baldwin has argued that

¹ R. J. Morris, *Cholera 1832: The Social Response to an Epidemic* (London, Croom Helm, 1976), pp. 95-118.

² C. Rosenberg, *The Cholera Years 1832, 1849 and 1866* (Chicago, University of Chicago Press, 1962).

³ E. H. Ackerknecht, 'Anticontagionism Between 1821-1867', *Bulletin of the History of Medicine*, 22 (1948), pp. 562-93.

this relationship was by no means straightforward.⁴ He highlights a more complicated history that emphasises the importance of political regimes, but also a wider set of social, medical and geographical factors that shape policy; for example the experience of dealing with epidemic threats, international trade, the emergence of bacteriology and a country's physical position in relation to an epidemic. Within a similar framework of analysis, Aisenberg has shown that the social response to disease revealed tensions between individual liberty and governmental intervention in nineteenth century France.⁵

In addition, the history of the social response to disease in the nineteenth century is often used to reveal developments within the field of public health.⁶ Once again, the response to the cholera epidemics is used to trace progress in public health in nineteenth century Britain and elsewhere.⁷ Much of the early work on the history of public health had outlined technical developments and sanitary reforms adopted to curb the spread of disease.⁸ Here, the narrative tone was essentially optimistic, describing the heroic progress made by public health initiatives. However, some

⁴ P. Baldwin, *Contagion and the State in Europe 1830-1930* (Cambridge, CUP, 1999).

⁵ A. R. Aisenberg, *Contagion: Disease, Government and the 'Social Question' in Nineteenth-Century France* (California, Stanford University Press, 1999).

⁶ J. Lewis, 'The Public's Health: Philosophy and Practice in Britain in the Twentieth Century', in E. Fee and R. M. Acheson (eds), *A History of Education in Public Health: Health that Mocks the Doctor's Rules* (Oxford and New York, OUP, 1991), pp. 195-229.

⁷ See, for example, D. Porter, *Health, Civilisation and the State: a History of Public Health from Ancient to Modern Times* (London and New York, Routledge, 1999), p. 88; M. W. Flinn, *Public Health Reform in Britain* (London and New York, Macmillan and St Martin's Press, 1968); Morris, *Cholera 1832*; M. Pelling, *Cholera Fever and English Medicine 1825-1865* (Oxford, OUP, 1976); M. Durey, *The Return of the Plague: British Society and the Cholera 1831-2* (London, Gill and Macmillan, 1979). For France, see F. Delaporte, *Disease and Civilization* (Cambridge, Mass., MIT Press, 1986); for Germany, see R. J. Evans, *Death In Hamburg: Society and Politics in the Cholera Years 1830-1910* (Oxford, Clarendon Press, 1988).

⁸ See, for example, W. Frazer, *History of English Public Health 1834-1939* (London, Baillière and Cox, 1950); J. H. F. Brotherston, *Observations on the Early Public Health Movement in Scotland* (London, H. K. Lewis & Co. Ltd, 1952); C. Fraser Brockington, *A Short History of Public Health* (London, Churchill, 1956); G. Rosen, *The History of Public Health* (New York, MD Publications, 1958); R. Lambert, *John Simon and British Sanitary Administration* (London, Macgibbon and Key, 1963); H. P. Tait, *A Doctor and Two Policemen: The History of Edinburgh Health Department 1862-1974* (Edinburgh, Mackenzie and Storrie, Public Health Department, 1974).

historians, who have explored the importance of broader social indicators of disease, such as the role of diet, have come to more pessimistic conclusions.⁹ While, others have shown this argument to be flawed, the debate over the role public health has played in eradicating disease continues.¹⁰

More recent studies on the social response to disease illustrate that the dynamics of public health initiatives are far from straightforward. Rather, policy-making is seen to have been extremely complex, involving negotiations and deliberations between medical, political, legal, religious and voluntary pressure groups. Examples include Hamlin's case study of the history of the development of nineteenth-century British water supply systems and sewers and Mooney's work on the Compulsory Infectious Disease Notification Acts in the late nineteenth century, the latter revealing the powerful role of medical practitioners in the policy-making process in Liverpool.¹¹

Other historians have used the social response to disease to study the broader spectrum of the public health movement. In particular they have examined the history of institutions, for example, isolation hospitals, to demonstrate changes in public health ideology, such as a shift from public hygiene and environmental sanitation, in favour of controlling individuals in isolation.¹² As Welshman points out, fewer

⁹ T. McKeown, *The Modern Rise of Population* (London, Edward Arnold, 1976).

¹⁰ See, for example, E. A. Wrigley and R. S. Schofield, *The Population History of England 1541-1871* (London, Edward Arnold, 1981); S. Szreter, 'The Importance of Social Intervention in Britain's Mortality Decline c1850-1914: A Reinterpretation of the Role of Public Health', *Social History of Medicine*, 1 (1988), pp. 1-37.

¹¹ C. Hamlin, *Public Health and Social Justice in the Age of Chadwick* (Cambridge, CUP, 1997); G. Mooney, 'Public Health versus Private Practice: the Contested Development of Compulsory Infectious Disease Notification in Late Nineteenth-Century Britain', *Bulletin of the History of Medicine*, 73 (1999), pp. 238-67.

¹² J. V. Pickstone, *Medicine and Industrial Society: A History of Hospital Development in Manchester and its Region, 1752-1946* (Manchester, Manchester University Press, 1985), pp. 156-83; J. M. Eyler, 'Scarlet Fever and Confinement: The Edwardian Debate over Isolation Hospitals', *Bulletin of the History of Medicine*, 61(1987), pp. 1-24.

studies have been carried out on public health in the late twentieth century due, in part, to its perceived decline as a medical specialty.¹³ Nonetheless, there are some exceptions, which also highlight the complexities of health policy formation, particularly within the constraints of a local setting.¹⁴

The medical response to disease is also used as a tool to gain insight into ways in which disease is socially constructed. Rosenberg and Golden's edited work on disease classification emphasises social and cultural factors that shape medical knowledge and explains how disease is both a biological and social phenomenon.¹⁵ Others have used the medical response to disease to show how debates on theories of disease causation and its treatment are linked to struggles for professional identity. Fee and Porter chart the establishment of preventative medicine as a new specialty in public health within the context of the rise of bacteriology in nineteenth century Britain and the United States.¹⁶ Similarly, Bryder's study of tuberculosis illustrates how the rise of surgical treatment over more conservative therapies may have had more to do with professional interests than medical outcomes.¹⁷

The Social Response to Sexually Transmitted Diseases (STDs) from 1800

¹³ J. Welshman, *Municipal Medicine: Public Health in Twentieth-Century Britain* (Oxford, Peter Lang, 2000), p. 26.

¹⁴ *Ibid*; J. Welshman, 'Compulsion, Localism and Pragmatism: the Micro-Politics of Tuberculosis', *Social History of Medicine*, 19:2 (2006), pp. 295-312.

¹⁵ C. Rosenberg and J. Golden (eds), *Framing Disease: Studies in Cultural History* (New Brunswick, New Jersey, Rutgers University Press, 1992).

¹⁶ E. Fee and D. Porter, 'Public Health, Preventive Medicine, and Professionalization: Britain and the United States in the Nineteenth Century', in E. Fee and R. M. Acheson (eds), *A History of Education in Public Health: Health that Mocks the Doctor's Rules* (Oxford and New York, OUP, 1991), pp. 15-43.

¹⁷ L. Bryder, *Below the Magic Mountain: A Social History of Tuberculosis in Twentieth-Century Britain* (Oxford, Clarendon Press, 1988), pp. 157-98.

The history of the social response to STDs¹⁸ has been instrumental in illuminating the social and cultural values held by society, especially in relation to morality. For example, anxieties and concerns over sexual behaviour in late nineteenth century America led to the perception of emergent venereal disease as symbolic of a society with corrupt sexual mores.¹⁹ Similarly, studies on the social response to STDs in Britain have revealed links between disease, morality and sexual behaviour.²⁰

A major focus of research has been placed upon the manner in which the state's response to STDs plays an important role in forming and reflecting perceptions of sexuality, especially with regard to gender. Historians interested in gender studies and women's histories have used the social response to STDs to shed light on the discriminatory nature of sexual health policies towards women. In these cases, such policies are seen to reinforce gender divisions in wider society and reflect fears about broader issues such as urbanisation and the displacement of female labour.²¹ Other historians have demonstrated how official policy and documents were underpinned by preconceptions of women as vectors of infection, reflecting the double standards of sexual morality at the time.²² The examination of medical opinions also demonstrates

¹⁸ For the purposes of this account, sexually transmitted diseases refer to diseases transmitted by sexual intercourse, except for Human Immunodeficiency Virus (HIV) or Acquired Immune Deficiency Syndrome (AIDS), which are dealt with in the following section.

¹⁹ A. M. Brandt, *No Magic Bullet: A Social History of Venereal Disease in the United States since 1880* (Oxford, OUP, 1985).

²⁰ See for example, R. Davidson, *Dangerous Liaisons: A Social History of Venereal Disease in Twentieth-Century Scotland* (Amsterdam, Rodopi, 2000); F. Mort, *Dangerous Sexualities: Medico-Moral Politics in England since 1830*, Second Edition (London, Routledge, 2000).

²¹ See, for example, J. Walkowitz, *Prostitution and Victorian Society: Women, Class and the State* (Cambridge, CUP, 1980); R. Davidson, 'Venereal Disease, Public Health and Social Control: The Scottish Experience in Comparative Perspective', *Dynamis Acta Hisp. Med. Sci. Hist. Illus.*, 17 (1997), pp. 343-9.

²² R. Davidson, *Dangerous Liaisons*, pp. 346-7; Brandt, *No Magic Bullet*, pp. 167-8; P. McHugh, *Prostitution and Victorian Social Reform* (London, Croom Helm, 1980).

how new scientific knowledge about STDs was linked to older notions of females as sexual polluters.²³

Studies on gender have also used the social response to STDs as a means of examining the way in which medical ideology linked prostitution with feeble-mindedness and provided justifications for the incarceration of offenders seen to be in need of moral guardianship.²⁴ Other research has explored the role played by women in campaigning against STD controls, drawing attention to broader patterns of resistance such as the control of women by medical practitioners, the double standards of sexual morality and the role of the state in regulating the sexual behaviour of the poorer classes.²⁵

Yet further studies have shown that STD policy has been shaped by a desire to control the sexual urges of young adolescents, reflecting concerns about the breakdown of family and community controls. As Brandt argues, the persistence of venereal disease was attributed to an increase in more liberal sexuality among youths in the twentieth century, rather than a decline in public health measures. Thus, those who aimed to control venereal disease did so by controlling the sexual behaviour of the young.²⁶ Davidson points to Scottish STD control measures that were informed by similar fears, especially with respect to the behaviour of girls and young women.²⁷

²³ See, for example, M. Spongberg, *Feminizing Venereal Disease: The Body of the Prostitute in Nineteenth-Century Medical Discourse* (London, Macmillan, 1997).

²⁴ See, for example, Davidson, *Dangerous Liaisons*, pp. 274-5; L. Mahood, *The Magdalenes: Prostitution in the Nineteenth Century* (London and New York, Routledge, 1990); P. Bartley, *Prostitution: Prevention and Reform in England 1860-1914* (London, Routledge, 1999).

²⁵ Walkowitz, *Prostitution and Victorian Society*; L. Bland, *Banishing the Beast: English Feminism and Sexual Morality 1885-1914* (London, Penguin Books, 1995).

²⁶ Brandt, *No Magic Bullet*, p. 126-9.

²⁷ Davidson, 'Public Health and Social Control', p. 349.

Issues on class and race have also arisen within the literature on STDs. In Britain, debates over STD control measures are seen as informed by middle-class values of abstinence, hygiene and self-restraint. For example, Walkowitz argues that medical treatment and practice were supported by the attitudes of the dominant classes in Victorian society which were reflective of anxieties about working class sexual behaviour.²⁸ Similarly, in twentieth-century Scotland, it has been argued that STD treatment and education espoused middle-class values in an attempt to moralise the poorer classes.²⁹

The social response to STDs also illustrates the ways in which control measures can both reflect and reinforce xenophobic beliefs about sexuality and disease, revealing wider attitudes and values about race. For example, studies on the social response to syphilis in America after the First World War have demonstrated how health strategies targeting racial groups were shaped by perceptions of syphilis as a black disease, the victims of which were deemed to have uncontrollable sexual instincts.³⁰

Some of the above issues regarding the discriminatory nature of STD policy have been shown to be especially prevalent during wartime when controls taken to curb STDs were more compulsionist in countries such as Britain and the USA. The measures are considered to be a reflection of anxieties about the impact of war on sexual behaviour, particularly with regard to women.³¹ Other studies have

²⁸ Walkowitz, *Prostitution and Victorian Society*, p. 55.

²⁹ Davidson, 'Public Health and Social Control', p. 352.

³⁰ Brandt, *No Magic Bullet*, pp. 157-8.

³¹ L. Bland, 'In the Name of Protection: The Policing of Women in the First World War', in J. Brophy and C. Smart (eds), *Women-in-Law: Explorations in Law, Family and Sexuality* (London, Routledge and Kegan Paul, 1985), pp. 23-49; E. H. Beardley, 'Allied against Sin: American and British Responses to Venereal Disease in World War I', *Medical History*, 20 (1976), pp. 189-202; L. A. Hall, 'Venereal Diseases and Society in Britain, from the Contagious Diseases Acts to the National Health

highlighted the role of the Armed Forces (especially the Medical Corps) and their influence upon the state's response to STD measures.³² Studies on British wartime policy-making during the First World War also stress the fragmentary nature of the policy-making process between military and civilian agendas, demonstrating the shortcomings of state strategy, which was far from unified.³³

The role of pressure groups in the health policy-making process has also been of interest to historians working on the social response to STDs. It has been shown that during the nineteenth century campaign to repeal the Contagious Diseases Acts, those in favour of repeal were not an homogenous late-Victorian pressure group but rather a complex amalgam of activists motivated by varying causes and concerns. Walkowitz argues that an unusual alliance between working-class men and middle-class women protested against doctors, both with differing aims and beliefs.³⁴ Further, medical pressure groups were divided over the extent to which medical responses should be shaped by moral considerations.³⁵

Similarly, the role played by pressure groups in influencing health policy in the twentieth century presents a complex picture of their relationship with government. For example, studies of the political debates surrounding Venereal Disease (VD) prophylaxis from 1916-1926 and the campaign for compulsionist legislation in inter-war Scotland indicate that policy-making was not simply a struggle between

Service', in R. Davidson and L. A. Hall (eds), *Sex, Sin and Suffering – Venereal Disease and European Society since 1870* (London and New York, Routledge, 2001). pp. 120-36.

³² B. A. Towers, 'Health Education Policy 1916-26: Venereal Disease and the Prophylaxis Dilemma', *Medical History*, 24 (1980), pp. 70-87.

³³ L. Bland, "'Cleansing the Portals of Life': The Venereal Disease Campaign in the Early Twentieth Century", in M. Langan and B. Schwarz (eds), *Crises in the British State 1880-1930* (London, Hutchinson, 1985), p. 193.

³⁴ Walkowitz, *Prostitution and Victorian Society*, pp. 141-3.

³⁵ Bland, "'Cleansing the Portals of Life'" pp. 192-208.

medicalists and moralists but a set of interactions between and within different departments of state, local authorities, public health institutions, and social hygiene and purity organisations, with the outcome on occasions influenced by the impact of powerful individual personalities.³⁶

Finally, much research has focussed more specifically on the role of the medical profession in the social response to STDS. For example, some studies have used the history of debates surrounding prophylaxis to shed light on the monopolizing strategies of medical practitioners in the policy-making process through their membership of voluntary organisations and consultancy committees and their direct influence upon the Ministry of Health.³⁷ Other studies have focused on the treatment of STDs to illustrate links between therapeutic treatment regimes and the rise of venereology as a medical specialty.³⁸

The Social Response to AIDS

Literature on the history of the social response to AIDS is extensive and varied.³⁹ The second half of the 1980s revealed some focus on the social response to AIDS in the context of past epidemics, and some of these studies are presented as ‘lessons of history’, providing the role of informing policy on the AIDS epidemic.⁴⁰ For

³⁶ Towers, ‘Health Education Policy 1916-26’; S. M. Tomkins, ‘Palmitate or Permanganate: The Venereal Prophylaxis Debate in Britain, 1916-1926’, *Medical History*, 37 (1993), pp. 382-98; R. Davidson, ‘“A Scourge to be Firmly Gripped”: The Campaign for VD Controls in Interwar Scotland’, *Social History of Medicine*, 6 (1993), pp. 213-35.

³⁷ Towers, ‘Health Education Policy 1916-26’, p. 71.

³⁸ Davidson, *Dangerous Liaisons*, pp. 91-7.

³⁹ I use the term AIDS here, as opposed to AIDS/HIV (Human Immunodeficiency Virus), since this is in keeping with the majority of historiographical material. However, where both terms have been used in the literature, I shall include them.

⁴⁰ See, for example, R. Porter, ‘History says No to the Policeman’s Response to AIDS’, *British Medical Journal*, 293 (1986), pp. 1589-90; E. Fee and D. M. Fox (eds), *AIDS: The Burdens of History*

example, the history of STDs is used to show the ways in which society has responded to epidemics. Prominent are parallels between AIDS and STDs concerning the relationship between disease and stigmatisation, the pros and cons of voluntarist versus compulsionist policies, and debates surrounding the civil rights of individuals versus the public good.

From the late 1980s, the history of the social response to AIDS has been ‘AIDS as history’.⁴¹ Over time AIDS has come to be viewed as less of an epidemic, and more of a chronic disease. In addition, social commentators from several disciplines, especially political science, have contributed to the history of the social response to AIDS. Studies range from the relationship between the disease and social groups, such as the gay movement, to studies on policy formation.⁴² Given the vast amount of literature on AIDS, this historiographical account is restricted to the relationship between disease and society, the relationship between disease and the state,

(Berkeley, Los Angeles and London, University of California Press, 1988); A. M. Brandt, ‘AIDS in Historical Perspective: Four Lessons from the History of Sexually Transmitted Diseases’, *The American Journal of Public Health*, 78 (1988), pp. 367-71.

⁴¹ See, for example, V. Berridge and P. Strong (eds), *AIDS and Contemporary History* (Cambridge, CUP, 1993); V. Berridge, *AIDS in the UK: The Making of Policy, 1981-1994* (Oxford, OUP, 1996); E. Fee and D. M. Fox (eds), *AIDS: The Making of a Chronic Disease* (Berkeley, Los Angeles, Oxford, University of California Press, 1992); C. Hannaway, V.A. Harden and J. Parascandola (eds), *AIDS and the Public Debate: Historical and Contemporary Perspectives* (Amsterdam, Oxford, Tokyo, and Washington D.C., IOS Press, 1995).

⁴² See, for example, P. Aggleton and H. Homans (eds), *Social Aspects of AIDS* (London, New York and Philadelphia, The Falmer Press, 1988); P. Aggleton, G. Hart and P. Davies (eds), *AIDS: Social Representations, Social Practices* (New York and London, The Falmer Press, 1989); P. Aggleton, P. Davies and G. Hart (eds), *AIDS: Individual, Cultural and Policy Dimensions* (London, The Falmer Press, 1990); P. Aggleton, P. Davies and G. Hart (eds), *AIDS: Rights, Risk and Reason* (London, Falmer Press, 1992); P. Aggleton, P. Davies and G. Hart (eds), *AIDS: Facing the Second Decade* (London, The Falmer Press, 1993); P. Aggleton, P. Davies and G. Hart (eds), *AIDS: Foundations for the Future* (London, Taylor and Francis, 1994); B. Almond (ed.), *AIDS: A Moral Issue – The Ethical, Legal and Social Aspects*, Second Edition (New York, St Martin’s Press, 1996); D. Altman, *AIDS and the New Puritanism* (London, Pluto Press Ltd, 1986); D. Altman, *Power and Community: Organizational and Cultural Responses to AIDS* (London, Taylor and Francis, 1994); E. Carter and S. Watney (eds), *Taking Liberties: AIDS and Cultural Politics* (London, Serpent’s Tail, 1989); D. L. Kirp and R. Bayer (eds), *AIDS in the Industrialized Democracies: Passions, Politics, and Policies* (New Brunswick, Rutgers University Press, 1992); D. Nelkin, D. P. Willis and S. V. Parris (eds), *A Disease of Society: Cultural and Institutional Responses to AIDS* (Cambridge, CUP, 1994).

particularly health policy formation, and the relationship between disease and medical and scientific developments.

For many historians and social commentators the social response to AIDS has been a source for the understanding of deeper cultural and moral values.⁴³ Some researchers have shown how perceptions of AIDS are closely linked to society's notions of and concerns about sex.⁴⁴ Others have used Stanley Cohen's concept of 'moral panic' to explain the discrimination against certain groups in society, such as gay men, injecting drug abusers and Haitians.⁴⁵ Cohen argues that, during periods of rapid social change, moral panics occur over issues considered to be a danger to the moral fabric of society. Such fears often result in the stigmatisation of social groups perceived as threats.

A number of studies use the social response to AIDS to reveal relations and structures in society. Voluntary organisations have played a key role in policy formation and service provision for people affected by AIDS. AIDS histories have thrown light on voluntarism in post-war society by demonstrating how voluntary organisations and their endeavours are developed and maintained.⁴⁶ Other accounts illuminate the way

⁴³ See, for example, Brandt, *No Magic Bullet*, pp. 183-204.

⁴⁴ Mort, *Dangerous Sexualities*.

⁴⁵ J. Weeks, 'Love in a Cold Climate', in Aggleton and Homans (eds), *Social Aspects of AIDS*, pp. 10-19; S. Watney, 'AIDS, 'Moral Panic' Theory and Homophobia', *Ibid*, pp. 52-64, S. Cohen, *Folk Devils and Moral Panics: The Creation of Mods and Rockers*, Third Edition (New York and London, Routledge, 2002).

⁴⁶ P. Aggleton, J. Weeks and A. Taylor-Laybourn, 'Voluntary Sector Responses to HIV and AIDS: A Framework for Analysis', in Aggleton, Davies and Hart (eds) *AIDS: Facing the Second Decade*, pp. 131-40; J. Weeks, A. Taylor-Laybourn and P. Aggleton, 'An Anatomy of the HIV/AIDS Voluntary Sector in Britain', in Aggleton, Davies, and Hart (eds), *AIDS: Foundations for the Future*, pp. 1-19; V. Berridge and P. Strong, 'AIDS Policies in the United Kingdom: A Preliminary Analysis', in Fee and Fox (eds), *AIDS: The Making of a Chronic Disease*, pp. 299-325; V. Berridge, "'The Unambiguous Voluntarism?'" - AIDS and the Voluntary Sector in the United Kingdom, 1981-1992', in Hannaway, Harden and Parascandola (eds), *AIDS and the Public Debate*, pp. 153-69; K. McCann, 'The Voluntary Sector, Gay Men and HIV/AIDS', in Aggleton, Davies and Hart (eds), *AIDS: Rights, Risk and Reason*, pp. 192-201; Z. Schramm-Evans, 'Responses to AIDS, 1986-1987', in Aggleton, Davies and Hart

in which society can respond to crises and demonstrate the potential for success or failure.⁴⁷ The response to AIDS by the UK voluntary sector has been explored within the context of health service reforms that emphasise a move from hospitals to Care in the Community.⁴⁸

Worldwide, the response of voluntary organisations to AIDS, which has frequently involved a challenge to state responses, has sometimes inadvertently led to a reduction of pressure upon governments to act effectively upon the spread of illness.⁴⁹ In this context, the growth of voluntary organisations has given rise to a number of tensions within the voluntary sector: between political activism and service, between altruism and self-help; and about the extent to which volunteers' participation is eroded by management control.

Ethnographic studies, focusing specifically on homosexual responses to AIDS, have attempted to explain the relationship between citizenship and geographic space, drawing on theories of radical democracy in an effort to understand the success and failure of activism within a contemporary society, undergoing changes affecting the state, civil society and family.⁵⁰ Research on the gay community and its organisations suggests that these may have been transformed, as many homosexuals came to 'own'

(eds), *AIDS – Individual, Cultural and Policy Dimensions* (London, The Falmer Press, 1990), pp. 221-32.

⁴⁷ S. C. O. Kobasa, 'AIDS Volunteering: Links to the Past and Future', in Nelkin, Willis and Parris (eds), *A Disease of Society*, pp. 172-88; R. Petchy, J. Williams, B. Farnsworth and K. Starkey, 'A Tale of Two (Low Prevalence) Cities: Social Movement Organisations and the Local Policy Response to HIV/AIDS', *Social Science and Medicine* 47, 3 (1998), pp. 1197-208.

⁴⁸ P. Aggleton, J. Weeks and A. Taylor-Laybourn, 'Voluntary Sector Responses to HIV and AIDS: A Framework for Analysis', pp. 131-40; J. Weeks, A. Taylor-Laybourn and P. Aggleton, 'An Anatomy of the HIV/AIDS Voluntary Sector in Britain', pp. 1-19; V. Berridge and P. Strong, 'AIDS Policies in the United Kingdom: A Preliminary Analysis', in Fee and Fox (eds), *AIDS: The Making of a Chronic Disease*, pp. 299-325; V. Berridge, 'The Unambiguous Voluntarism? AIDS and the Voluntary Sector in the United Kingdom, 1981-1992', pp. 153-69.

⁴⁹ Altman, *Power and Community*.

⁵⁰ M. P. Brown, *Replacing Citizenship: AIDS Activism and Radical Democracy* (New York and London, Guildford Press, 1997).

the AIDS epidemic and took charge of services, which strengthened their sense of identity and belonging.⁵¹

A further aspect of the social response to AIDS as a means of exposing wider social relations is the link between disease and gender. Treichler examines the language of AIDS to demonstrate ways in which medical discourse constructs sex and sexuality and reinforces cultural notions of gender.⁵² Another example is a focus on the gendered nature of biomedicine, which equates sexual health with heterosexual man and sees women, bisexual and gay men as the vectors of disease.⁵³ Within this framework, it has been argued that women have often been discriminated against with regard to testing and screening initiatives.⁵⁴ The examination of medical and scientific discourse also shows how constructs of sex and sexuality can reinforce notions of homophobia and xenophobia.⁵⁵ Health education campaigns are also seen to reinforce and shape cultural notions of gender.⁵⁶ Likewise, other studies focussing on men's issues have shown how cultural ideologies and expectations can shape men's vulnerability to disease.⁵⁷

⁵¹ R. A. Padgug and G. M. Oppenheimer, 'Riding the Tiger: AIDS and the Gay Community', in Fee and Fox (eds), *AIDS: The Making of a Chronic Disease*, pp. 245-78; Altman, *AIDS and the New Puritanism*; J. Weeks, 'Male Homosexuality: Cultural Perspectives', in M.W. Adler (ed.), *Diseases in the Homosexual Male* (Berlin, Heidelberg, Springer-Verlag, 1988), pp. 1-13.

⁵² P. A. Treichler, 'AIDS, Gender, and Biomedical Discourse: Current Contests for Meaning', in Fee and Fox (eds), *AIDS: The Burdens of History*, pp. 190-266.

⁵³ C. Waldby, *AIDS and the Body Politic: Biomedicine and Sexual Difference* (New York, Routledge, 1996).

⁵⁴ L. Sherr, 'HIV Testing in Pregnancy', in C. Squire (ed), *AIDS and Women: Psychological Perspectives* (London, Sage, 1993), pp. 42-68.

⁵⁵ On homophobia see, S. Watney, 'AIDS, 'Moral Panic' Theory and Homophobia'; P. A. Treichler, *How to have a Theory in an Epidemic: Cultural Chronicles of AIDS* (Durham and London, Duke University Press, 1999), pp. 11-4. On xenophobia see, C. Patton, *Inventing AIDS* (New York and London, Routledge, 1990), pp. 77-87.

⁵⁶ See, for example, D. Richardson, 'AIDS Education and Women: Sexual and Reproductive Issues', in Aggleton, Davies and Hart (eds), *AIDS: Individual, Cultural and Policy Dimensions*, pp. 169-79.

⁵⁷ P. Mane and P. Aggleton, 'Gender and HIV/AIDS: What Do Men Have to Do with It', *Current Sociology*, 49 (2001), pp. 23-37.

The social response to AIDS has also been used to shed light on the mass media, with the power to influence as well as to reflect perceptions of disease and sexuality.⁵⁸ Some research has used AIDS as an example of how the media can misinform, distort and select types of evidence over others, performing a disservice for health education rather than the opposite.⁵⁹ Within this framework of analysis, it is argued that AIDS was used by the media to appeal to voyeurism, fear and prejudice, which helped to reinforce notions of 'moral panic' and homophobia.⁶⁰ Berridge's work on the relationship of the media to the policy process in Britain describes a four stage parallel process between the media and policy response to AIDS between 1981-1991.⁶¹ For example, she argues that the press presentation of AIDS, particularly as a 'gay plague' had little impact on policy, while television played an important role in reinforcing a consensual approach to AIDS prevention policies.

The policy response to AIDS is an important part of the social response to AIDS and the historical literature reflects this. A comparative analysis of the policy response to AIDS in industrialized democracies is used to reveal the relationship of disease to each nation's political culture, emphasising the ways in which AIDS lays bare the political, social and cultural characters of society.⁶² Within this context, Baldwin also stresses the importance of a 'deep historical public health memory' to the

⁵⁸ T. E. Cook and D. C. Colby, 'The Mass-Mediated Epidemic: The Politics of AIDS on the Nightly Network News', in Fee and Fox (eds), *AIDS: The Making of a Chronic Disease*, pp. 84-122.

⁵⁹ K. Wellings, 'Perceptions of Risk – Media Treatments of AIDS', in Aggleton and Homans (eds), *Social Aspects of AIDS*, pp. 83-105.

⁶⁰ See, for example, Altman, *AIDS and the New Puritanism*; J. Meldrum, 'The Role of the Media and the Reporting of AIDS', in Almond (ed.), *AIDS: A Moral Issue*, pp. 71-81; S. Watney, 'AIDS, 'Moral Panic' Theory and Homophobia'.

⁶¹ V. Berridge, 'AIDS the Media and Health Policy', *Health Education Journal*, 50 (1991), pp. 179-85.

⁶² Kirp and Bayer (eds), *AIDS in the Industrialized Democracies*.

understanding of the divergences in the response to AIDS among the industrialised nations.⁶³

A number of commentators have explored the relationship between policy formation and pressure group input. Some have argued that the medical profession has had more influence over government in the UK than gay groups.⁶⁴ Others, interested in the scientific construction of AIDS, have contrasted the role of epidemiologists and virologists to demonstrate how their particular models of disease have informed policy at different stages of the epidemic.⁶⁵

Two broad strands of interpretation regarding the relationship of AIDS to state policy in the UK stand out. The first argues that the state's response to AIDS is best described as part of a 'New Right reaction' in the 1980s, that reflected 'moral panic', the stereotyping of its sufferers, and the call for greater surveillance and proscription of sexual lifestyles.⁶⁶ Alternatively, the second argues that the government response to AIDS has been determined by the liberal values of the traditional biomedical elite and reflects the 'power of professionalism'.⁶⁷ However, Berridge has argued for a more nuanced approach to the history of AIDS policy-making and identifies four phases of development in the period 1981-94.⁶⁸ While her model incorporates elements of both of the above strands, it offers further insights into the pattern of

⁶³ P. Baldwin, *Disease and Democracy – The Industrialized World Faces AIDS* (Berkeley, Los Angeles, London, University of California Press, 2005).

⁶⁴ J. Street, 'British Government Policy on AIDS: Learning Not to Die of Ignorance', *Parliamentary Affairs*, 41 (1988), pp. 490-507.

⁶⁵ G. M. Oppenheimer, 'In the Eye of the Storm: The Epidemiological Construction of AIDS', in Fee and Fox (eds), *AIDS: The Making of a Chronic Disease*, pp. 267-300.

⁶⁶ J. Weeks, 'AIDS: The Intellectual Agenda', in Aggleton, Hart and Davies, *AIDS: Social Representations, Social Practices*, pp. 1-20.

⁶⁷ D. M. Fox, P. Day and R. Klein, 'The Power of Professionalism: AIDS in Britain, Sweden and the United States', *Daedalus*, 118 (1989), pp. 92-112; P. Day and R. Klein, 'Interpreting the Unexpected: The Case of AIDS Policy-Making in Britain', *Journal of Public Policy*, 9 (1989), pp. 337-53.

⁶⁸ Berridge, *AIDS in the UK*.

government response over this period. In particular, she stresses the unprecedented role of pressure groups such as gay groups and new medical specialties (eg, virology), not previously included within the health policy-making process, the essential 'Wartime' emergency effects of AIDS on the policy making structure, the changing definition of AIDS from an 'epidemic' disease to a 'chronic' disease, and the change in consensus towards increased screening and surveillance.

Studies on local policy responses remain scarce, especially in Scotland. There are two exceptions, both within the social science tradition of research. The first describes patterns of response to AIDS in eight English District Health Authorities (DHAs) and one Scottish Health Board, and demonstrates the role of crises in stimulating organisational change.⁶⁹ Analysed within the context of organisational theory, this study highlights the diversity of local policy-making at the level of the DHA, drawing attention to the degree of autonomy, especially the innovatory role of strong local personalities acting as 'clinical product champions' responsible for driving change in local health service configuration. The second exception is a thesis in defence of the actor-network approach as a tool of analysis in order to explain the process of health policy formation.⁷⁰ Lothian HIV/AIDS policy from 1987-1997 is used as one case study wherein the importance of pioneering doctors in providing the impetus for policy implementation is emphasised.

⁶⁹ E. Ferlie and A. Pettigrew, 'Coping with change in the NHS: a Frontline District's Response to AIDS', *Journal of Social Policy*, 19 (1990), pp. 191-200; E. Ferlie, 'The NHS Responds to HIV/AIDS', in Berridge and Strong, *AIDS and Contemporary History*, pp. 203-23. See, also, C. Bennett and E. Ferlie, *Managing Crisis and Change in Health Care: The Organizational Response to HIV/AIDS* (Oxford, OUP, 1994).

⁷⁰ P. A Cairney, 'The Network-Actor Approach to Policy Networks: Case Studies from Health and HIV/AIDS Policy Implementation in Britain', Unpublished PhD Thesis (University of Strathclyde, 1999).

Attention has also been given to the social response to AIDS in order to understand wider developments within the medical and scientific sectors. Rosenberg's work on the social construction of disease and its cultural meanings focuses on the power of the medical profession, linking changes in definition of disease to the expansion of medical prestige and authority.⁷¹ In contrast, a study of the social response to AIDS by the French medical profession argues that the crises over contaminated blood were representative of a much wider conflict amongst doctors who believed their autonomy was being eroded by the state.⁷²

Finally, a number of studies have focussed on the medical response to AIDS as a prism through which to view developments within public health. A study of public health doctors illustrates the process by which they re-aligned themselves to the changing definitions of AIDS from an 'epidemic' to a 'chronic' disease.⁷³ Changes in definition are seen to reflect a broader shift within public health, from matters concerning social and environmental determinants of health towards a 'new public health', with more emphasis on individual prevention. Other studies have discussed public health developments in the context of debates over issues such as compulsory testing and screening for Human Immunodeficiency Virus (HIV) as a means of exploring discord between the need to protect civil liberties and the need to protect public health.⁷⁴

⁷¹ C. Rosenberg, 'Disease and Social Order in America: Perceptions and Expectations', in Fee and Fox (eds), *AIDS: The Burdens of History*, pp. 12-32.

⁷² A. M. Moulin, 'Reversible History: Blood Transfusion and the Spread of AIDS in France', in Hannaway, Harden and Parascandola (eds), *AIDS and the Public Debate*, pp. 170-86.

⁷³ J. Lewis, 'Public Health Doctors and AIDS as a Public Health Issue', in Berridge and Strong (eds), *AIDS and Contemporary History*, pp. 37-54.

⁷⁴ See, for example, R. Bayer, 'AIDS, Privacy and Responsibility', *Daedalus*, 118 (1989), pp. 79-100; A. M. Brandt, 'AIDS: From Social History to Social Policy', in Fee and Fox (eds), *AIDS: The Burdens of History*, pp. 147-71; *Idem*, 'AIDS in Historical Perspective: Four Lessons from the History of Sexually Transmitted Diseases'; D. Porter and R. Porter, 'The Enforcement of Health: The British Debate', in Fee and Fox (eds), *AIDS: The Burdens of History*, pp. 97-120; T. Stoddard and W. L.

Limitations to Existing AIDS Literature

Arguably, a central weakness of the existing literature on the history of AIDS is that, in furnishing an aggregate picture of the policy response to AIDS, it sheds little light on local responses within the United Kingdom. As Berridge observes, 'AIDS was a national issue; but it was also strongly influenced by localism'.⁷⁵ Additional research is needed to document the nature and extent of such influences, bearing in mind that Scotland continues to be shaped by distinctive traditions of law, education, religion, local government, medical practice, and arguably a distinctive civic and sexual culture.

A number of strands to this central weakness may usefully be identified. First, the medical politics of AIDS at a local level deserves additional treatment. In a period when new specialities (such as virology) were gaining access to the policy-making process and old specialties such as venereology and public health were acquiring a new lease of life in terms of funding and status, it is valuable to explore the tensions between such specialties at the local level. This is more so in Scotland, where medical strategies towards AIDS were increasingly polarized between infectious disease and sexually transmitted disease (STD) perceptions of AIDS. Conflict between medical perceptions of AIDS and those of other professionals or laypersons also need to be further explored at the local level.

Rieman, 'AIDS and the Rights of the Individual: Toward a More Sophisticated Understanding of Discrimination', in Nelkin, Willis and Parris (eds), *A Disease of Society*, pp. 241-71; D. Richardson, 'AIDS Education and Women: Sexual and Reproductive Issues', in Aggleton, Davies and Hart (eds), *AIDS: Individual, Cultural and Policy Dimensions*, pp. 169-79.

⁷⁵ Berridge, *AIDS in the UK*, p. 287. More recently, historians such as John Pickstone have also emphasised the importance of 'localism' as a key part of historical scholarship. See, J. V. Pickstone, 'Medical History as a Way of Life', *Social History of Medicine*, 18, (2005), pp. 307-23.

Secondly, the existing historiography emphasises the role of voluntary groups and the balance of initiative between voluntarism and the state at the national level. Studies of this interface at the local level remain limited. Bennet and Ferlie's research on District Health Authorities, including one in Scotland, explored the role played by the National Health Service at the local level and its interactions with the voluntary sector.⁷⁶ However, little attention and detail was paid in any depth to cultural differences in Scotland. Furthermore, research has not addressed the extent to which different types of voluntary groups (especially voluntary drug groups) were involved at different stages of local policy formation. Given that Edinburgh was unique in terms of the nature of transmission of HIV as a result of drug injecting misusers sharing needles, further analysis is required to understand the variation in response to disease in this locality between the voluntary and statutory sectors.

Thirdly, a common theme in the literature is how the social response to AIDS may reflect wider cultural notions of sexuality and gender, particularly with respect to the nature of health education campaigns. This is also examined at the aggregative level only, whereas an exploration of this relationship at the local level is required. For example, a distinct health education campaign ('Take Care') was launched in Lothian, which has yet to be examined.

Fourthly, much of the existing literature emphasises the role of the mass media in influencing and reinforcing perceptions of disease and sexuality and its relationship to policy development. Much of the data is based on newspaper and television coverage of national media or media outwith Britain. An analysis of the impact of Scottish

⁷⁶ Ferlie, 'The NHS Responds to HIV/AIDS'; See, also, Bennett and Ferlie, *Managing Crisis and Change in Health Care*.

media coverage and its relationship to local policy and how notions of disease and sexuality were reinforced or challenged by such coverage is lacking.

Finally, a leitmotiv within AIDS policy literature is the ongoing debate over compulsion with respect to containment, treatment, screening and contact tracing. Further analysis is required to examine the extent to which local groups or individuals in Edinburgh contributed to these debates, especially debates around the introduction of needle exchanges in the UK. This liberal response seems at odds with traditional approaches in Scotland where a more compulsionist outlook had been favoured, particularly with respect to STDs.⁷⁷

Aims of Research

There are two main aims to this study. The first is to provide an in-depth historical account of the Edinburgh response to AIDS, 1982-1994 as a means of illuminating wider issues brought to bear upon the formation of health policy at the local level. A second and related aim is to compare and contrast this local study with research carried out on the national responses to AIDS in the UK, particularly the work of Virginia Berridge.⁷⁸ This research will build upon and complement previous and current research on sexual health policy in Scotland by Professor Roger Davidson and Dr Gayle Davis within the Department of Economic and Social History, University of Edinburgh.⁷⁹ Their research furnishes a pre-history of AIDS in Scotland, addressing similar issues: the competing claims of public health and civil liberties, the relative

⁷⁷ R. Davidson, *Dangerous Liaisons*.

⁷⁸ Berridge, *AIDS in the UK: The Making of Policy, 1981-1994*.

⁷⁹ Wellcome Trust Funded Research Project, 'Health Sexuality and the State in late Twentieth-Century Scotland, 1950-1980'.

weighting of governmental and voluntary agencies in the policy-making process, the importance of the 'Local State' in shaping initiatives, and the competing interests both within the medical profession and more broadly between medical, legal, educational and cultural responses to the disease.

Sources

This study of policy-making in Edinburgh exploits a wealth of material from a wide range of archives covering the work of the Scottish Office, the Lothian Health Board (LHB), voluntary agencies and pressure groups. Predominantly, these sources are located at the National Archives of Scotland (NAS) and Lothian Health Services Archive (LHSA), University of Edinburgh. The records that have been used fall into three broad categories.

1. Government Records

These records contain information, ranging from memoranda to briefing documents, relating to every aspect of the AIDS question in government. They include AIDS files created by the Scottish Home and Health Department (SHHD), the Scottish Education Department (SED) and Scottish Office Central Services (SOSC). The subjects cover AIDS and blood transfusion, drug misuse, health education, medical practices, prisons, treatment and rehabilitation, and research in Scotland, as well as ministerial correspondence. These papers provided valuable insights into policy-making decisions at both local and national level (Scotland).

Prior to the introduction of the Freedom of Information (Scotland) Act of 2002, which was implemented in early 2005, I was granted 'privileged access' to closed files by the NAS. I undertook that no information relating to individuals would be published, delivered or broadcast without prior permission from the Scottish Executive. Afterwards some files were exempted and access was withdrawn. The extent to which the exempt material may have affected my findings is unknown.

2. *Lothian Health Services Archive*

Special access to AIDS-related records held by the LHSA was negotiated with the LHB under conditions similar to those of the NAS. These documents are especially rich in data and have not been used before. A survey concluded that, taken together they 'are of outstanding significance in documenting all aspects of the history of HIV and AIDS in Lothian and Scotland generally'.⁸⁰ Of particular relevance to this thesis has been the Lothian Regional AIDS Team Papers – (1986-1994) – GD24. This Team was set up in 1986 in response to the recommendations made in the McClelland Report (1986) on 'HIV Infection and Intravenous Drug Misuse'.⁸¹ The LHB AIDS Co-ordinator, Dr George Bath, who died in 1994, was the creator of these files. They contain government reports, annual and evaluation reports of various statutory and non-statutory organisations, minutes, agendas and papers of meetings of various committees, ranging from the SHHD, LHB and Lothian Regional Council (LRC) to voluntary/inter-agency committees, and correspondence and administrative files of the AIDS Team itself. This material provides insights into the health service response

⁸⁰ J. Foster, *Lothian Health Services Archive – HIV and AIDS Collections: A Survey and Report* (Unpublished Report, 2002), p. 1.

⁸¹ Scottish Home and Health Department, *HIV Infection in Scotland: Report of the Scottish Committee on HIV Infection and Intravenous Drug Misuse* (Edinburgh, 1986).

to AIDS as well as the response of national and local government and voluntary organisations.

These papers also contain the minutes and papers of the Regional AIDS Group (1986-1994) and the Lothian AIDS Forum (1987-1994), which are particularly comprehensive and important for the purposes of this study. Both committees were initiated by the LRC to assist their AIDS co-ordinator in developing a corporate response to AIDS. These groups were composed of representatives from the LRC, Edinburgh District Council, the LHB, the police and eventually a number of voluntary groups. Furthermore, a newsletter, 'Meridian' was produced by the AIDS Team, between 1989 and 1996 and is also contained in these files. This provided information on every aspect of HIV/AIDS as it occurred in Edinburgh, acting as a useful resource to those working in the field and also included, in a number of issues, profiles of all government and non-government organisations involved in aspects of AIDS.

The files of the 'Take Care' Campaign - (1988-1997) - GD22 have also proved an important resource for the purposes of this thesis. They relate to a local public health campaign spearheaded by the LHB AIDS Team's Health Promotion Specialist and funded jointly with the LRC. The material sheds light on how the campaign evolved during the HIV/AIDS crisis in Edinburgh. These files also contain a folder of local news clippings pertaining to the campaign.

In addition, the Lothian Health Board AIDS Papers - (1991-1996) - LHB45 have been utilised. These contain correspondence (including that of the Director of Public

Health), medical and scientific reports on AIDS transmission, epidemiology and treatment, guidance notes for health care workers, surveys and publicity material on education policy. Related to these are the papers of the Director of Public Health/Chief Area Medical Officer for Lothian - (1988-1997) - GD25. Although there is some considerable overlap between these papers and those of the Lothian Regional AIDS Team papers, they deal with aspects of the involvement of the Director's response to AIDS in Lothian. No similar collection elsewhere in the UK has yet been identified.⁸²

3. *Other Records:*

Media sources - Newspapers/Magazines

Scottish newspaper articles, especially those from the *Scotsman*, the *Edinburgh Evenings News* and *Scotland on Sunday* (launched in 1988) have been researched covering the period 1981-1994 in order to assess the extent to which they influenced or reinforced local AIDS policy. *Gay Scotland*, a bi-monthly magazine aimed at homosexuals was also researched for this period, to examine the homosexual community's response to AIDS.

The Medical Press

Medical journals were a useful resource and provided information on debates during the AIDS epidemic. In particular, *AIDS*, the *Lancet*, the *British*

⁸² Foster, p. 5.

Medical Journal, the *Scottish Medical Journal* as well as a local medical journal, *Edinburgh Medicine*, were used, covering the period 1981 - 1994.

Published Reports

Published Reports (UK, Scottish and local) on the response to AIDS were consulted and utilised as a means of comparing and contrasting national and local responses to AIDS. Individual reports are listed in the Sources and Bibliographical Section of this thesis.

Pressure Groups and Voluntary Organisations

The papers and annual reports of a range of local voluntary and Scottish organisations were consulted to determine the extent to which pressure/voluntary groups were involved in AIDS initiatives in Edinburgh. These included the Scottish Branch of the British Medical Association; Church of Scotland; Scottish Catholic Church, CRUSAID Scotland; Free Presbyterian Church of Scotland; Scottish AIDS Monitor; Save the Children Fund Scotland; Scottish Homosexual Rights Group and the Scottish Society for the Study of Venereal Diseases. These papers have furnished insight into the nature and timing of the response of voluntary organisations to the AIDS crisis.

Interview Data

The decision not to undertake any structured interviews or oral histories was made during the early stages of the project. Time constraints due to the volume and wealth of written records on AIDS in Edinburgh formed the main reason for this decision. However, had there been enough time, it is unclear as to how representative the interview sample would have been. This is because of ongoing litigation cases by haemophiliacs in Edinburgh who believe they were misinformed about the risks of HIV/AIDS and Hepatitis C during the 1980s. Their story has since featured in the press and formed part of a BBC Scotland *Frontline* programme entitled, 'Blood and Tears', which was shown in June 2005.⁸³ Another allegation has been that haemophiliacs were used as guinea pigs during research into HIV/AIDS. This allegation was also followed up by BBC Scotland *Frontline* in a programme entitled, 'Patients Used for Blood Trials', screened in April 2007.

Some haemophiliacs have given evidence to a private inquiry (The Archer Inquiry), which commenced in early 2007. The new Scottish Government announced in April 2008 its intention to carry out a Scottish public inquiry into the infection of patients with hepatitis C and HIV through blood products.⁸⁴ This inquiry is to be chaired by former judge and sheriff, Lady Cosgrove. A total of £3 million has been earmarked for the inquiry and evidence will be taken towards the end of 2008.

It became apparent during informal interviews with some key individuals in Edinburgh that not all key players in the AIDS/HIV story, especially those

⁸³ J. McBeth, 'Families of Six Who Died from Infected Blood Start Legal Fight', *The Scotsman*, 10 May 2005.

⁸⁴ 'Tainted Blood Inquiry Announced', see www.news.bbc.co.uk/scotland, 23 April 2008.

involved in blood products, might be willing to participate. Given the sensitive and legal nature of these issues, it was decided not to pursue this method of data collection further. However, it would be highly appropriate to undertake a separate study based on in-depth interviews or oral histories some time after the inquiry has taken place as a means of complementing this study.

Nonetheless, during a preliminary survey of archive material at the LHSA, two documents were found which contained interview material from a number of individuals who were involved in the response to AIDS in Edinburgh between 1982-1994. The first of these documents appears to be a draft government report of a study on the NHS AIDS provision in Lothian carried out by a researcher from Warwick University, Chris Bennett, who was the co-author of the published study, *Waiting for AIDS: The Response to HIV Infection in Lothian*.⁸⁵ This document is rich in qualitative interview data upon the response to AIDS, particularly from staff at the LHB, which is not included in the final draft of the report. The second document is a 41-page draft proposal for a paper/book on the HIV epidemic in Edinburgh, which was also based on interviews with key players in Edinburgh.⁸⁶ Although these documents are in draft form, interview material is contained within them, and this has been utilised for the purposes of this thesis as a source of secondary data to provide a valuable complementary source to the type of data found in the written records mentioned above.⁸⁷

⁸⁵ Lothian Health Services Archive [LHSA], Edinburgh University Library [EUL], GD24, C6, D1 (10), Draft Document by C. Bennett, 'AIDS in Lothian Case Study'. See, C. Bennett and A. Pettigrew, *Waiting for AIDS: The Response to HIV Infection in Lothian – Summary Report* (Centre for Corporate Strategy and Change, University of Warwick, September 1989).

⁸⁶ LHSA, EUL, GD25, B6, Document, 'Draft Outline: Confidential', 12 August 1996.

⁸⁷ N. Blaikie, *Designing Social Research* (Cambridge, Polity Press, 2000), pp. 183-226.

In addition, interview material from the 'Remember When' project that was set up by the Living Memory Association in Edinburgh to document oral histories of the lives and achievements of Edinburgh's Lesbian, Gay, Bisexual and Transgender population, past and present, was used to glean information on the responses to AIDS. These can be found at www.rememberwhen.org.uk.

Limitations to the above Sources

A number of general limitations to the above sources are evident. Firstly, the sheer volume of material was a particular difficulty. For example, the Lothian Regional AIDS Team Files (GD24) located at the Lothian Health Services Archive consists of around 40 large boxes, half of which contain around 15 files each and the other half containing the contents of the AIDS Team's library of official reports. In addition, there are around 90 voluminous files of Scottish Office government records held at the National Archive of Scotland. The content of some files did not correspond with the title of the file, which made a selection strategy impossible and meant that every file was examined in detail. This was a time-consuming process and contributed to the decision not to carry out in-depth interviews and/or oral histories.

Time constraints also made it impossible to examine all Scottish media sources (especially the *Edinburgh Evening News*, the *Scotsman* and *Scotland on Sunday*) year by year, from 1981 – 1994 in the time available. Both the *Edinburgh Evening News* and the *Scotsman* newspapers were produced daily, except for Sundays, meaning that over 9000 newspapers would have to have been investigated. Therefore, press

cuttings found in the Scottish Office and LHB files in connection with policy issues or complaints from pressure groups over discrimination were used to save time. Also, media sources were examined in relation to developments in policy. For example, when government or local policy decisions were taken, the media sources were examined before, during and after decisions were taken to explore the extent to which the media influenced or reinforced policy.

Secondly, there is the issue of how representative the surviving documents are. For example, it is clear that many of the government records relate to issues surrounding AIDS and drug misuse, especially between 1986 and 1987. This probably reflects the most pressing issues that concerned government during the AIDS crisis in Scotland, such as needle exchange. Alternatively, it is conceivable that it is an artefact of record keeping practices.

Likewise, sources relating to the statutory response to AIDS may not be fully representative. Edinburgh City Archives Department had no records of the response to AIDS from the LRC or Edinburgh District Council. However, as mentioned above, the Lothian Regional AIDS Team papers (GD24) were used to fill in this gap, particularly copies of the minutes, agenda, papers and correspondence of the Regional AIDS Group and the Lothian AIDS Forum, both of which were founded by the LRC. The LRC's AIDS co-ordinator acted as chairman, alternating this position with George Bath, the AIDS co-ordinator for LHB. Thus, a complete set of LRC AIDS papers was contained in the files created by George Bath. Material relating to the Edinburgh District Council's response was also contained in these files, especially the Environment Health Department's response. Its Director, Richard Carson and George

Bath had been involved in the response to Hepatitis B in the City in the early 1980s and papers relating to this period were also contained in these files.

Similarly, the sources employed may not be fully representative of the role of voluntary groups in policy-making. While every effort was made to provide a cross-section of different types of groups, the Scottish AIDS Monitor (SAM), one of the main Edinburgh voluntary organisations, could not be consulted. SAM disbanded in 1996 in acrimonious circumstances and its own records have not been located. Instead, information about SAM in government files (on funding and education), in LHASA files (representation on the Regional AIDS Group and the Lothian AIDS Forum) and *Gay Scotland* magazine (HIV/AIDS and the gay community) has been used. In addition, a meeting with the former Chief Executive of SAM, Mrs Maureen Moore, was also carried out to ascertain more about the organisation's history.

Other voluntary group records, especially drug projects, also proved difficult to track down. Attempts were made to contact some projects that were involved in the early response to AIDS in Edinburgh but with little success. It would appear that some projects were short-lived or may have been renamed. However, Lothian Regional AIDS Team Papers contain a wealth of information on voluntary groups, particularly their input into inter-agency committees, annual reports, evaluation reports (especially on those funded by the LHB) and correspondence between them and the statutory sector.

Access to the records of the Scottish Haemophiliac Society also proved difficult. An email letter was sent to their Secretary based upon information provided by the UK

Haemophiliac Society. No reply was received. Given that some members could be involved in the current litigation cases, it was decided not to pursue access to this organisation's records any further.

A third limitation relates to the type of document and the level of detail it provides. For example, minutes of committees/groups can often be cryptic, providing little evidence of the policy decision-making process. However, care has been taken to analyse minutes in relation to surviving pre-circulated papers of meetings in order to provide more insight into particular policy decisions.

Similarly, a number of Annual Reports have been consulted, particularly those produced by the Lothian Regional AIDS Team from 1988 onwards for the purposes of the AIDS (Control) Act 1987. These contained a wealth of information about the local response to AIDS. While these were intended to inform government about the locality's co-ordinated approach to AIDS, they would also have been produced to encourage government to fund further measures to contain the spread of AIDS. Thus the extent to which statistics may have been manipulated to attract funding has been considered.

Media sources also require careful consideration when being evaluated for the purpose of research.⁸⁸ For example, the *Scotsman* is a national broadsheet, whilst the *Edinburgh Evening News* is a local tabloid newspaper. It could be argued that the tabloid press is more liable to produce lurid, sensationalised accounts, designed to

⁸⁸ A. Giddens, *Sociology* (Oxford, Polity Press, 1992), pp. 676-7.

appeal to the health fears and sexual prurience of the reader. Therefore, such sources were researched with this possibility in mind.

While recognising the above limitations of sources, I believe that the variety of data collected has allowed me to compare, contrast and verify sources against each other in order to provide the most objective account of the events occurring in response to AIDS in Edinburgh during the period defined.

Methodology

The principle method of research has been a qualitative case study analysis of archive material to identify the dynamics of Edinburgh-based HIV/AIDS policy-making and to compare and contrast these findings with that of the national findings on AIDS policy making in the UK. In many ways Edinburgh makes an ideal case study. Depicted as the ‘AIDS Capital of Europe’, the City figured prominently in debates about the epidemiology and treatment of AIDS.⁸⁹ The experience of sexual health and drug policies in Lothian fed into UK policy-making. The dramatic implications for transmission of HIV/AIDS to the heterosexual population, based upon local incidence figures, were fully aired. Finally, there were distinctive features of AIDS policy in Scotland, for example in relation to health education, clinical input and blood transfusion, that varied markedly from the rest of the UK.

⁸⁹ C. Dawson, ‘Babies of the ‘AIDS Capital’’, *The Sunday Telegraph*, 13 April 1986. This study specifically focuses on Edinburgh since it was the city, and not the whole of Lothian Region, that experienced the highest incidence of HIV in the mid-1980s. However, reference will be made to Edinburgh and Lothian Region (sometimes used interchangeably) in the context of figures and statistics that were produced by Lothian Health Board and Lothian Regional Council, both of which covered Edinburgh and the surrounding Lothian region.

Case studies are often criticised because they tend to be based on qualitative data. Some have argued that such data makes the research difficult to replicate as there is too much scope for the researcher to influence the results.⁹⁰ This criticism seems to be made by those who believe that only quantitative data can be used to describe and explain social life validly and reliably. I would argue that objectivity is difficult to achieve using either qualitative or quantitative data. Design and analysis will, to some extent, depend on the values of the researcher and also on the aims of the research. One can strive towards objectivity by adopting the most impartial method and this has been attempted in this thesis. Also, the main aim of this thesis is to explore the dynamics of local policy-making including the influence of individual personalities. Therefore, qualitative data is the most appropriate and valid method of data collection for this purpose.

A further criticism of case studies is that it is not possible to make generalisations about the social world.⁹¹ However, this research is not concerned with generalisations. Rather one of the aims is to highlight the degree of variance, which can be obtained locally, from the general picture of AIDS policy-making in the UK.

The case study has been carried out by constructing a chronological narrative of events using Berridge's stadial model of AIDS policy-making in the UK.⁹² This is a framework of analysis of policy-making with which to compare and contrast local and national responses to AIDS. The stadial model comprises four distinct phases of the policy-making response to AIDS between 1981 and 1994. Phase One of this model is

⁹⁰ Blaikie, p. 218.

⁹¹ F. Bechhofer and L. Paterson, *Principles of Research Design in the Social Sciences* (London and New York, Routledge, 2000), p. 48.

⁹² Berridge, *AIDS in the UK*.

between 1981 and 1985.⁹³ This is characterised as a period when policy was a 'bottom up' rather than a 'top down' process. Groups, such as gay activists, and medical and scientific experts formed a 'policy community' who saw the need to respond to the emergence of AIDS. This was a time of 'self help', where little government intervention took place, particularly in the early 1980s. After the discovery of the AIDS virus in 1983-1984 some government departments began to take notice with the realisation that AIDS was a threat to all. During 1985, the growing concern about AIDS gained a higher level of political interest and gave rise to a debate over appropriate action. A liberal consensus around AIDS emerged, based on post-war health policy-making traditions, legitimised by scientific and medical experts, as opposed to a 'New Right' reaction characterised by punitive measures which discriminated and stigmatised groups.⁹⁴

Phase Two of Berridge's model focuses on the period 1986 - 1987, which she describes as the 'Wartime Response', characterised by a high level of government intervention which was shaped by a perception of AIDS as a national crisis that required action on a scale akin to that of the Second World War.⁹⁵ The crisis response was a liberal consensual response to AIDS prevention, one which stressed the importance of safe sex and harm minimisation rather than the espousal of a moral agenda advocating no sex and no drugs. The response was neither a 'New Right' reaction nor a traditional policy-making reaction legitimised by medical experts, since it included a bureaucratic strategy of 'respectable out' for Ministers concerned about their involvement in controversial issues. At the same time, it allowed Ministers to intervene when they felt the need.

⁹³ *Ibid*, pp. 13-78.

⁹⁴ *Ibid*.

⁹⁵ *Ibid*, pp. 81-152.

Phase Three of the AIDS policy response concentrates on the period between 1987 and 1989.⁹⁶ At this time the response to AIDS moved into a new phase of 'Normalisation and Chronic Disease'. This period witnessed a shift in definition of AIDS from an 'epidemic' disease to a 'chronic' disease, influenced by epidemiological studies, which suggested that the rate of growth of the incidence of the disease had slowed down. The shift in definition of AIDS was also influenced by the development of treatments, such as AZT (Azidothymidine/Zidovudine). AIDS came to be perceived as a 'normal' disease like many other chronic conditions of the late twentieth century, which were treatable. This shift in definition coincided with a departure from the liberal consensus around AIDS, with greater emphasis on screening and testing, especially anonymous testing. Also, within this phase tensions arose within the voluntary sector, where original volunteer roles were being increasingly undermined and replaced with paid professional posts, due to the expansion of funding.

The final Phase occurred between 1990 and 1994 and is described as the period of 'the Repoliticization of AIDS'.⁹⁷ This period witnessed the downgrading of AIDS as a policy issue as epidemiology continued to refute the threat of an immediate heterosexual epidemic. AIDS began to lose its special status, with reduced funding, and came to be perceived as any other chronic disease. This was also a time when the gay community began to fragment. Some gay groups sought to re-introduce the connections between AIDS and homosexuality. Other gay groups went beyond AIDS and became more concerned about wider issues such as sexual health. Another

⁹⁶ *Ibid*, pp. 155-227.

⁹⁷ *Ibid*, pp 231-79.

feature of this phase is the continuing erosion of the liberal consensus and the abolition of funding for the drug voluntary sector. However, a liberal response was maintained in some areas, particularly with respect to policy concerning prisons. Thus, by the early, 1990s, AIDS was simultaneously being mainstreamed and marginalized.

Structure of Thesis

Within Berridge's framework of analysis of AIDS policy-making, a number of themes are explored and examined. These include the changing perceptions of AIDS in Edinburgh and its impact on the shifting balance of power between the local state and voluntary agencies in the policy-making process; the respective roles of the health, education and policing arms of central and local government; the role of and interaction between a variety of social, professional and sexual pressure groups, with especial emphasis on that of the medical profession and competing specialities within it; and the contribution of the Scottish media in reinforcing 'moral panic' surrounding HIV/AIDS and policy formation.

After localising the study of AIDS policy-making in Edinburgh within a broader context of policy-making in response to STDs and drug misuse prior to 1985 (Chapter 2), the thesis consists of four main parts. Part 1 of the thesis is concerned with the early response to AIDS between 1982 and 1985. Chapter 3 of this section deals with the years 1982-1984 and charts the initial response to AIDS by the local gay and medical communities. Chapter 4 focuses on the year 1985, highlighting a period of

increasing government intervention amid concerns about blood supplies and the discovery of HTLV-III amongst intravenous drug misusers.

Part 2 explores the response to AIDS between 1986 and 1987. Chapter 5 concentrates on early 1986 and discusses measures that focussed on women, reflecting perceptions of them as vectors of disease. Chapter 6 pays attention to the period after the publication of the McClelland Report and explores debates surrounding the introduction of measures to contain AIDS which were deemed to be controversial, particularly health education, needle and syringe exchange and methadone substitution therapy.

Part 3 examines the period between mid 1987 and 1989. Chapter 7 of this section deals with measures introduced from mid-1987, and concentrates on some of the recommendations outlined in the Tayler Report.⁹⁸ These include the provision of an AIDS Unit at the City Hospital, an AIDS Hospice and the introduction of wider screening measures for antenatal women. Chapter 8 focuses on developments within drug policy that indicate a move towards liberal measures of control against AIDS. This chapter also explores the development of a local education campaign, 'Take Care', which highlighted fears about heterosexual spread in Edinburgh as did perceptions of AIDS as an 'epidemic' disease.

Part 4 focuses on the period 1990-1994. Chapter 9 assesses the influences behind further preventative measures against HIV leading to targeted health education campaigns with a particular focus on the sex industry. This chapter also reveals

⁹⁸ Scottish Home and Health Department, *Report of the National Working Party on Health Service Implications of HIV Infection* (Edinburgh, May 1987).

ongoing tensions between the statutory and non-statutory sectors, which led to the restructuring of some of the groups that had been formed in the 1980s. Chapter 10 deals with developments in drug misuse policy in response to HIV, leading to an increasingly liberal approach within prisons in Scotland and also examines new initiatives in screening and testing which highlighted a shift in attitude about the importance of these measures in the prevention of HIV.

Chapter 11 forms the concluding chapter, which revisits Berridge's stadial model of AIDS policy-making in the UK in the light of the Edinburgh evidence. This discusses the differences between the UK and Edinburgh responses to AIDS in more detail, emphasising the importance of local and Scottish constraints in defining AIDS policy, and summarising the broader implications of the study. This chapter also locates some of the main themes identified in the thesis within the context of the historiography of the social response to disease. A final section highlights further areas for research on the history of AIDS policy-making in Edinburgh.

CHAPTER 2 – THE POLICY RESPONSE TO DRUG MISUSE AND SEXUALLY TRANSMITTED DISEASES IN EDINBURGH – 1965 - 1985

The purpose of this chapter is to provide a brief account of the policy response to drug misuse and Sexually Transmitted Diseases (STDs) in Edinburgh prior to the emergence of AIDS. This account serves as a prelude to the following chapters because it demonstrates that the history of the policy response in these areas contributed to the explanation of the policy response to AIDS.

Drug Misuse Policy in Edinburgh – 1965 – 1985

As with other parts of the UK during the 1960s, drug misuse in Edinburgh came to be perceived as a problem. Edinburgh police statistics for illegal possession of selected drugs under the Dangerous Drugs Act 1965 show an increase from 10 convictions to 131 over the six-year period, 1966-1971.¹ The response to this perceived problem was two-fold, consisting of a legal approach, which entailed harsher sentencing for those found in possession of drugs, and a medical approach to treat drug misuse, dominated by abstinence programmes, as opposed to long-term heroin or methadone maintenance therapy.

The Legal Response to Drug Misuse

The legal response was initiated in the mid 1960s with the introduction of a Drug Squad, consisting of a small team of officers operating within the Aliens, Firearms

¹ Scottish Home and Health Department, Second Report of the Sub-Committee of the Consultative Committee of Medical Officers of Health, *Misuse of Drugs in Scotland* (Edinburgh, HMSO, 1972), p. 5.

and Dangerous Drugs Department. The majority of their work concentrated upon chemist shop break-ins and surveillance of prescription patterns issued by medical practitioners.² By the 1970s the misuse of drugs had become intimately linked with the former and this appears to have motivated the Drug Squad to lobby for more punitive measures.

The 1980s witnessed an increased use of heroin in Edinburgh. A survey carried out by the police found that 34.5% of crimes relating to house break-ins were associated with drug misuse.³ The result of this survey led to a further increase in Drug Squad resources, with the addition of a sergeant and four acting officers.⁴ Further punitive strategies were employed across all levels of drug misuse activity. Users were often perceived to be involved in the supply of drugs and charges brought against them often reflected this.⁵ In addition, police activity included an informal policy of stop and search, which led to the confiscation of injecting equipment as a means of preventing further drug misuse.⁶ Any needles found on drug misusers were used as incriminating evidence and could lead to a long-term prison sentence. At the same time, it had been alleged that the main supplier of needles and syringes, which was located in the City's Bread Street area, was forced to close down under police pressure.⁷

² N. Olley, 'From Morningside to Muirhouse: Towards a Local Governance of the Self in Drug Policy', Unpublished Ph.D Thesis (University of Edinburgh, 2002), p. 61.

³ Lothian and Borders Police, *Report of the Chief Constable of Police* (Lothian and Borders Police, Edinburgh, 1983), p. 48.

⁴ Olley, p. 105.

⁵ *Ibid*, p. 107.

⁶ R. Robertson, 'The Edinburgh Epidemic: A Case Study', in J. Strang and G. Stimson (eds), *AIDS and Drug Misuse: The Challenge for Policy and Practice in the 1990s* (London and New York, Routledge, 1990), pp. 95-107.

⁷ R. Brett, 'Did the Band Play On?', *The George Bath Memorial Lecture*, Royal College of Physicians of Edinburgh, 15 May 1986, p. 4.

It has been argued that the above measures led to an increase of needle sharing in Edinburgh. This, in turn, was viewed as having contributed to an outbreak of Hepatitis B there in the early 1980s.⁸ Gatherings of 10-20 drug users sharing one needle and syringe were reported to be found in 'shooting galleries', often held in derelict houses.⁹ The response by the Edinburgh District Council Environmental Health Department had been to promote more lenient measures such as the introduction of sterile needles and syringes to curb the spread of Hepatitis B.¹⁰ However, this recommendation was rejected in favour of more police resources. The Police Board recommended the enhancement of the Drug Squad to the Scottish Home and Health Department (SHHD) at the Scottish Office and, by 1984, its size had doubled.¹¹

The Medical Response to Drug Misuse

From the 1960s, the medical response to Edinburgh's drug problem was undertaken by psychiatrists. Under the terms of the Dangerous Drugs Act (1967) a total of six psychiatrists had been issued with a special licence, which allowed them to prescribe

⁸ *Ibid*, p. 6.

⁹ J. R. Robertson, A. B. V. Bucknall, P. D. Welsby, J. J. K. Roberts, J. M. Inglis, J. F. Peutherer, and R. P. Brett, 'Epidemic of AIDS Related Virus (HTLV-III/LAV) Infection Among Intravenous Drug Abusers', *British Medical Journal*, 292 (1986), pp. 527-9.

¹⁰ LHSA [Lothian Health Services Archive], EUL [Edinburgh University Library], GD24, C5, D2, (2.2.0), Regional AIDS Group General (Part 1), Document, R. A. Carson, 'AIDS as a Communicable Disease – A Discussion Document and City Strategy', 1987.

¹¹ C. Bennett and A. Pettigrew, 'Waiting for AIDS: The Response to HIV Infection in Lothian – Summary Report', (Centre for Corporate Strategy and Change, University of Warwick, 1989), p. 6. The Scottish Home and Health Departments (SHHD) merged in 1983 during a reorganisation of the Scottish Office, which comprised five departments. In addition to the SHHD there was the Department of Agriculture and Fisheries for Scotland, the Scottish Development Department, the Scottish Education Department and the Scottish Economic Planning Department. The Scottish Office was located in Edinburgh and complemented by a liaison office in Dover House, Whitehall. The Ministerial team consisted of the Secretary of State, a Minister of State and three Under-Secretaries of State. See J. G. Kellas, *The Scottish Political System*, Fourth Edition, (Cambridge, Cambridge University Press, 1989), pp. 27-61; D. Butler and G. Butler, *Twentieth-Century British Political Facts, 1900-2000*, Eighth Edition, (Palgrave, Macmillan, 2000), p. 457.

heroin in the treatment of drug addiction.¹² Up until then, General Practitioners (GPs) had treated drug addiction but many were restricted from prescribing heroin under the new Act.¹³

Treatment was offered in the new Edinburgh Drug Treatment Centre, which opened in 1968 at the Royal Edinburgh Hospital. Treatment protocols consisted of admission as an in-patient for withdrawal under methadone or daily attendance for methadone on a gradually reducing dose. There was a strict policy not to prescribe heroin on an out-patient basis in case this had the effect of attracting addicts to the City.¹⁴ The Centre was not separate within the Royal Edinburgh Hospital but was integrated into the general adult psychiatric wards. There was no provision for additional medical, nursing or social work staff and treatment was carried out as part of the normal course of duties.¹⁵ This was in contrast to some parts of the UK where separate Drug Dependency Units existed.¹⁶ The SHHD saw little need to fund a separate unit in Edinburgh, or elsewhere in Scotland. The Chief Medical Officer (CMO) for Scotland's Consultative Committee of Medical Officers concluded that, although 'there are indications that drug misuse has become more prevalent in Scotland in recent years and must be a continuing cause for concern, the problem in terms of damage to the nation's health is relatively small, particularly when it is compared with

¹² M. Woodside, 'The First 100 Referrals to a Scottish Drug Addiction Treatment Centre', *British Journal of Addiction*, 68 (1973), p. 231.

¹³ R. Yates, 'A Brief History of British Drug Policy, 1950-2001', *Drugs: Education, Prevention and Policy*, 9:2 (2002), pp. 113-24; V. Berridge, 'AIDS and British Drug Policy: Continuity or Change?' in V. Berridge and P. Strong (eds), *AIDS and Contemporary History* (Cambridge, Cambridge University Press, 2002), pp. 135-56; P. Connell and J. Strang, 'The Creation of the Clinics: Clinical Demand and the Formation of Policy' in J. Strang and M. Gossop (eds), *Heroin Addiction and Drug Policy: The British System* (Oxford, New York and Tokyo, Oxford University Press, 1994), pp. 167-77; J.A. Ward, 'The Drug Scene in Scotland', *Scottish Medical Journal*, 16 (1971), pp. 376-9.

¹⁴ Woodside, 'The First 100 Referrals to a Scottish Drug Addiction Treatment Centre', p. 240.

¹⁵ *Ibid*, p. 231.

¹⁶ Berridge, 'AIDS and British Drug Policy: Continuity or Change?', pp. 135-56.

the much wider effects of cigarette smoking and alcoholism'.¹⁷ The priority given to alcoholism is reflected in the SHHD and Lothian Health Board (LHB) financial support for a separate alcohol unit at the Royal Edinburgh Hospital, which came into being in 1963.¹⁸

Throughout the 1970s medical treatment for drug addiction in Edinburgh remained unsatisfactory. The lack of resources was compounded by disillusion amongst the majority of psychiatrists, who began to question the appropriateness of a psychiatric model to treat drug misuse. Some psychiatrists felt that many drug addicts were undeserving of treatment because they 'did not establish good relationships with either staff or other patients, and had a disruptive influence on ward morale'.¹⁹ This view led to a shortage of professionals willing to treat drug misusers. As a result only one psychiatrist was working with drug misusers, reserving half a day per week for the treatment of approximately 10 patients.²⁰ Many drug misusers found it difficult to tolerate the detoxification programme and frequently abandoned treatment. Others did not perceive themselves to be mentally ill and found the length of stay required difficult to sustain in a ward that accommodated a variety of psychiatric conditions. The sole psychiatrist changed his treatment policy in favour of an out-patient methadone maintenance programme in the early 1970s, having visited the United

¹⁷ Quoted in, Scottish Home and Health Department, Second Report of the Sub-Committee of the Consultative Committee of Medical Officers of Health, *Misuse of Drugs in Scotland* (Edinburgh, HMSO, 1972), p. iii.

¹⁸ B. Ritson, 'Services for Problem Drinkers in Scotland' in M. Plant, B. Ritson and R. Robertson (eds), *Alcohol and Drugs: The Scottish Experience* (Edinburgh, Edinburgh University Press, 1992), pp. 130-7.

¹⁹ Woodside, 'The First 100 Referrals to a Scottish Drug Addiction Treatment Centre', p. 238.

²⁰ Olley, 'From Morningside to Muirhouse', p. 49.

States where this type of therapy was being introduced.²¹ Methadone maintenance therapy became popular throughout other parts of the UK at this time.²²

The methadone treatment administered by the psychiatrist was initially in tablet form but soon changed to ampoule form, for injection by the misuser, when it was realised that many drug misusers were crushing their tablets to inject it into their veins. A further change took place with respect to opening injecting facilities at the hospital to prevent the sell of methadone on the black market. A room was added to the out-patients department where injection could be carried out upon receipt of methadone. However, this was short-lived when confrontations occurred between young aggressive male drug misusers and 'middle class Morningside depressed ladies', using the same facilities.²³ The consultant became increasingly demoralised and 'disheartened and alert to the fact that what I gave, however it was arranged, either they managed to sell some of it or they were using it plus anything they could get their hands on'.²⁴

A limited number of GPs were involved in the treatment of drug misuse during the 1970s. However, the majority shared similar reservations to psychiatrists and were reluctant to treat drug addiction. As a result, one surgery started to attract more and more drug misusers, many of whom were outwith the practice area, and had to take steps to restrict patient numbers. At the same surgery, treatment policies of reduction, detoxification and maintenance co-existed with limited success. Unlike their psychiatric colleagues, GPs were subject to scrutiny from the Drugs Squad and the

²¹ *Ibid*, p. 51.

²² Berridge, 'AIDS and British Drug Policy: Continuity or Change?', p. 140.

²³ Olley, 'From Morningside to Muirhouse', p. 52.

²⁴ *Ibid*, p. 53.

Home Office Inspectorate who were responsible for monitoring levels of prescribed drugs. One doctor recalled a visit from the Home Office Inspector, where he received the view that his treatment regime was somewhat too liberal.²⁵

By the early 1980s little had changed in the psychiatric treatment offered to drug misusers in Edinburgh.²⁶ In 1983, a Joint Working Party on Drugs Abuse (JWPDA) in Lothian had been set up, on the initiative of the Lothian Regional Council (LRC). Its membership included representatives from the LRC, the LHB, the Police and the Edinburgh District Council (EDC). Part of its remit was to gather information on existing problems in areas where there was a high incidence of drug abuse and examine the implications for policies and practice.²⁷ A statement issued to the JWPDA by Edinburgh psychiatrists claimed that 'unless there [were] exceptional circumstances, eg, an illness such as diabetes, the normal policy is not to maintain addicts on heroin or methadone'.²⁸ They also informed the JWPDA of growing cynicism amongst staff because of the lack of a full-time specialist consultant in drug addiction within the LHB.²⁹ Lothian had a Senior Registrar post, which had been funded by the European Community Fund in the early 1980s and, although this had been converted to a Consultant post, it was only on a part-time and non-specialist basis. The LHB had recognised the need for hospital staff to be available to liaise with outside drug groups and had submitted a community-based project to the SHHD for funding around the same time but this had not been approved.³⁰

²⁵ *Ibid*, p. 60.

²⁶ A. B. V. Bucknall, J. R. Robertson and J. G. Strachan, 'Use of Psychiatric Drug Treatment Services by Heroin Users from General Practice', *British Medical Journal*, 292, (1986), pp. 997-9.

²⁷ LHSA, EUL, GD24, B3, Document, 'Joint Working Party on Drug Abuse in Lothian, Progress Report', (Lothian Regional Council, 1984), p. 3.

²⁸ *Ibid*, Appendix.

²⁹ *Ibid*, p. 9.

³⁰ *Ibid*.

This lack of dedicated medical treatment for drug misusers was noted by the Edinburgh Drug Addiction Study Group (EDASG), which included Dr Roy Robertson, a practising GP in Muirhouse, an area of high drug misuse and socio-economic deprivation. The Group argued that 'withdrawal may form only a minor part of treatment because heroin abuse, like alcohol abuse, is a remitting and relapsing disorder'.³¹ They believed that a community-based multidisciplinary treatment would be more appropriate because it would maintain contact with those drug misusers who relapsed and could offer flexible treatment to take account of the different needs of individuals. Together with voluntary drug workers, Robertson and other professionals had formed the Edinburgh Drug Abuse Action Group (EDAAG), all of whom felt strongly that different approaches to the management of drug abuse should be tailored to suit individual drug misusers and their families.³² Many in the EDAAG argued that boredom was a major factor leading to drug misuse, particularly in areas of high unemployment.³³

Collaboration between different agencies and a move towards a multi-disciplinary approach was in line with the recommendations outlined in the Report of the Advisory Council on the Misuse of Drugs (ACMD), *Treatment and Rehabilitation*, published in 1982.³⁴ Following this Report, the Department of Health established a Central Funding Initiative (CFI), which, from 1983 to 1987, furnished £17.3 million

³¹ A. B. V. Bucknall, J. R. Robertson and J. G. Strachan, 'Use of Psychiatric Drug Treatment Services by Heroin Users from General Practice'.

³² LHSA, EUL, GD24, B3, Joint Working Party on Drug Abuse in Lothian, Progress Report (Lothian Regional Council, 1984), p. 13.

³³ *Ibid.*

³⁴ Department of Health and Social Security, Advisory Council on the Misuse of Drugs, *Treatment and Rehabilitation* (London, 1982), p. 83.

towards the development of community-based services for drug misusers.³⁵ Edinburgh received a proportion of this funding and by 1984, the SHHD had made money available to five voluntary drug projects in Edinburgh, which offered counselling and support services to drug misusers.³⁶ However, there remained a lack of support by the SHHD for extra psychiatric services for the treatment of drug misuse.

Around the same time as these discussions were taking place, an outbreak of Hepatitis B occurred within Edinburgh's drug-taking community. This led some doctors to adopt an unofficial policy of supplying fresh needles and syringes in an attempt to curb the spread of disease.³⁷ Although a vaccine had become available, it was considered to be too expensive for wider distribution and in short supply.³⁸ Therefore, only hospital staff at 'high risk' of infection were immunised. Those suffering from symptoms of Hepatitis B were treated at the Infectious Diseases Unit (IDU) at the City Hospital. This Unit was well acquainted with the needs of Hepatitis B sufferers since it had treated patients during a previous outbreak in 1969, which resulted in a number of deaths, particularly amongst hospital staff.³⁹

Drug Misuse Education

In 1985 the Scottish Office provided funding to launch a major anti-drugs campaign throughout Scotland. This was the 'Choose Life not Drugs' campaign initiated by the

³⁵ V. Berridge, 'AIDS and British Drug Policy: Continuity or Change?', p. 141.

³⁶ D. Allsop and W. Slavin, 'Scottish Voluntary Alcohol and Drug Services', in M. Plant, B. Ritson and R. Robertson (eds), *Alcohol and Drugs: The Scottish Experience* (Edinburgh, Edinburgh University Press, 1992), p. 127.

³⁷ Brettle, 'Did the Band Play On?', p. 6.

³⁸ C. Bennett and A. Pettigrew, 'Waiting for AIDS: The Response to HIV Infection in Lothian', p. 5.

³⁹ *Ibid.*

Scottish Health Education Group (SHEG), whose approach was to tackle drug misuse as part of a broader health education campaign. The SHEG was the national agency responsible for health education in Scotland. It was formed in 1980 as the result of a merger between the Scottish Health Education Unit and the Scottish Council for Health Education and was controlled by the Management Committee of the Common Services Agency (CSA), which was part of the SHHD.⁴⁰ Members of the group were drawn from medical, nursing, social science, educational, marketing and media backgrounds.⁴¹ SHEG's message focussed on enhancing self esteem and confidence within individuals in order to deal with life's demands and prepare those 'at risk' from drug misuse in order to resist pressures from peers. They argued that education programmes should be targeted towards those 'at risk', and not just drug misusers.⁴² This approach was in contrast to England and Wales where campaigns attempted to coerce or change the habits of drug misusers by a combination of alarm and fear, and were seen to reinforce the legal approach to drug misuse.⁴³

We can see from the above that a number of reactions occurred over the course of the two decades up to 1985 in response to drug misuse in Edinburgh. The Home Department of the SHHD invested money in police resources and the Health Department supported a major drug misuse education campaign. The SHHD had also received money from the CFI to support voluntary drug projects. However,

⁴⁰ The CSA was designed to serve the Secretary of State for Scotland and Health Boards. It took over services that provided health on an all-Scotland basis such as prescription charges, dental estimates, health education, ambulance and blood transfusion. See, for example, J. Brotherston, 'The NHS in Scotland – 1948-1984' in G. McLachlan (ed) *Improving the Common Weal – Aspects of Scottish Health Services 1900-1984* (Edinburgh, Edinburgh University Press), pp. 103-59.

⁴¹ For further details on SHEG see NAS [National Archives of Scotland] HH61/1259, Document, 'SHEG – What It Is and What It Does', April 1987.

⁴² LHSA, EUL, GD24, B3, Joint Working Party on Drug Abuse in Lothian, Progress Report (Lothian Regional Council, 1984), p. 5.

⁴³ V. Berridge, *AIDS in the UK: The Making of Policy, 1981-1994* (Oxford, Oxford University Press, 1996), p. 193.

reluctance to develop psychiatric services for drug misuse remained. Psychiatrists had become unhappy both with the lack of support and the psychiatric model for treatment of drug misuse. In addition, drug misusers did not see themselves as having a problem that required a stay in a psychiatric hospital. Thus, by 1985 the response to drug misuse consisted of a harsh penal response combined with an inadequate medical response.

Sexually Transmitted Disease Policy in Scotland and Edinburgh - 1965 - 1985

From 1965, figures for STD cases in Scotland began to take an upward turn, with significant rises reported in gonorrhoea (particularly between 1968 and 1974) and 'new' STDs, such as male non-specific urethritis (NSU) and female trichomoniasis.⁴⁴ These figures continued to rise until the mid-1980s. Of growing concern to many social and medical commentators was the rise in the incidence of STDs among those in the 15-24 year old age group. These concerns fed into wider medical and moral debates over the permissive culture within Scotland's youth, particularly young women. Links were made between the rise in STDs and what was perceived to be a decline in family and spiritual values and the emergence of a morally corrupt youth culture. Of especial concern were young promiscuous females who were viewed as the 'reservoirs of infection'. These perceptions existed up to 1980, as did prejudices and assumptions about homosexual behaviour, which also identified 'passive' homosexuals as 'reservoirs of infection'.

⁴⁴ Unless otherwise stated the following account is based on the work of R. Davidson, *Dangerous Liaisons: A Social History of Venereal Disease in Twentieth-Century Scotland* (Amsterdam, Rodopi, 2000) Chs, 10-13.

The lack of support from the Department of Health for Scotland (DHS) for the provision of STD services after the Second World War was reflected in the recognition and standing given to the specialty of venereology by the DHS, and Regional Hospital Boards. Hospital Boards made no attempt to institute the specialist status of venereology when staffing their STD departments and the specialty was accorded a low ranking within the medical profession itself. Furthermore, no representation of the specialty existed within the DHS, where matters concerning STDs were discussed within an Infectious Disease forum.

Despite the rise in the incidence of STDs from the mid 1960s, and the publication of the *BMA Report on VD and Young People*, published in 1964, amongst others, the specialty continued to lack professional sway in Scotland. However, in the 1970s further pressure from the media, and Department of Health initiatives, resulted in the establishment of a joint Sub-Committee on Sexually Transmitted Diseases (known as the Gilloran Committee) in 1971 whose remit was to advise on such issues as the epidemiology, treatment and control of STDs in Scotland. Their report emphasised the need for urgent improvement of STD facilities and services. The Committee also recommended an increase of consultant posts in Venereology in order to provide a comprehensive service, as well as increased training for all medical undergraduates, general practitioners, nurses and contact tracers.

Yet, the publication of the Gilloran Report (1973) coincided with the imminent reorganisation of the National Health Service and financial constraint. Thus, whilst acknowledging the need to improve STD services, the new Area Health Boards (AHBs) were given no scope to commit themselves to extra financial outlays or

reconfiguration of existing budgets. Many Scottish venereologists continued to pressurise the SHHD to persuade AHBs of the need to provide sufficient resources for STD services. The SHHD did little to convince Health Boards to act accordingly. Some venereologists felt such a response was less of a reflection of financial constraints and more of a reflection of beliefs that patients with STDs were undeserving. By the early 1980s, the specialty of venereology remained chronically under-resourced, as did the STD treatment and prevention measures outlined below.

Treatment

Scotland witnessed dramatic advances in the treatment of STDs after the Second World War, especially with the introduction of new forms of chemotherapy. However, the effectiveness of this treatment in curbing the spread of STDs was hindered by a number of factors, including variations in the quality of treatment between urban and rural locations, the types of diagnostic tests available, the limitations of the impact of new antibiotics in treating the full range of STDs, together with the lack of funding to provide adequate facilities and services.

Health Education

The growing concern with sexual promiscuity amongst the young in Scotland and the rise in STDs led to the establishment of a new Scottish Health Education Unit (SHEU) in 1968. This produced a set of posters and literature targeted at youths, which outlined the dangers of casual sexual encounters. While efforts had been made

towards a less gendered content, the preoccupation with women as the main vector of disease was evident in some of the information.

Outwith such efforts, health education remained a low priority in the eyes of the SHHD, especially at a time of cutbacks in public spending throughout the 1970s. Moreover, the SHEU considered other health-related issues, such as smoking, alcoholism, immunization and family planning to be of greater importance. A number of local projects were undertaken in the late 1960s and 1970s, which included a telephone advice service, but sex education in schools throughout Scotland remained uneven into the 1980s. Some educationalists believed that education in sexual matters should be the preserve of teachers, whilst others felt it was the role of medical personnel to teach sex education as part of a wider health education programme. The Scottish Education Department (SED) considered sex education to be highly sensitive and preferred to refrain from issuing guidelines, believing that the initiative should come from individual schools. Tensions existed between the SED, the SHHD and the SHEU over whether or not there should be specialist teachers for sex education in schools. In 1976, attempts were made to create better working relations between the three in the form of a working group, but these fell apart because of the politically sensitive nature of the subject, which was currently being debated in House of Lords. An added constraint was the stance of Scottish churches, which were adamant that sex education in schools should be set within a programme upholding Christian values and morals.

While some venereologists felt that health education materials were not effective enough in targeting the promiscuous, others argued that the limited success in

educating the general public may in part have been due to the moral undertones that shaped much of the material. Medical literature in the 1970s could be laden with value judgements upon social behaviour as well as clinical descriptions. For example, those who had sexual intercourse outwith a 'normal' heterosexual relationship were deemed responsible for transmitting disease, particularly young girls. Furthermore, health education literature continued to focus on heterosexual relations, implicitly supporting the view that any other sexual relations, such as homosexuality, were immoral or abnormal. The absence of any mention of preventative methods such as the use of condoms also emphasised the moral agenda shaping policy. Some clinicians and contact tracers did offer confidential advice to their patients regarding the use of condoms, but such advice was given off the record. Thus, until the 1980s the concept of 'safe sex' tended to be defined in official discourse as a function of marriage and monogamy rather than as one purely of 'safety' within the sexual act per se.

Contact Tracing

A 1965 report by a Scottish Medical Advisory Committee Working Party on *The Incidence, Epidemiology and Control of Gonorrhoea in Scotland* recommended a more intensive contact tracing policy, especially by Social Workers. Contact tracing involves the clinic undertaking to advise sexual contacts named by patients. The Committee were concerned that contact tracing was not being thoroughly carried out in many parts of Scotland due to a lack of resources, poor relations between medical and social work personnel, and the absence of initiative on the part of Regional Health Boards to use Local Authority Health Visitors. The exceptions were Glasgow and

Edinburgh, whose STD clinics carried out a systematic process of contact tracing that involved the use of Social Work Departments. For example, in Edinburgh, almost 50% of new cases at a male Venereal Diseases (VD) clinic had been contact-traced and encouraged to undergo treatment and as many as 44% of first-time female patients who attended clinics had done so in response to contact tracing, compared with 16% in 1951.

In 1968 the Ministry of Health issued new guidelines designed to improve the effectiveness of contact tracing. However, the SHHD failed to respond to these or to the previous Report, believing that STD figures in Scotland did not pose a major health problem and that Hospital Boards were providing adequate facilities. The Department also harboured continuing doubts over the promotion of a contact tracing service in view of legal advice that health authorities could not be protected from litigation under Scots Law for slander and libel should information be disclosed in the course of tracing. Nonetheless, by 1970, a guidance booklet was produced for all doctors in Scotland which outlined the benefits of contact tracing.

The Gilloran Committee highlighted the significance of contact tracing as a means of containing the spread of STDs, especially by providing treatment for the main vectors of disease, such as 'promiscuous women' and 'passive homosexuals'. It also noted the variability of contact tracing services throughout Scotland and recommended standardisation with provision of adequate facilities to achieve this, in addition to the development of a career structure for contact tracers.

By 1978, the SHHD review of STD facilities demonstrated a highly variable provision of contact tracing services, with many areas in need of urgent resources to improve facilities. Even by 1985 the contact tracing service in Scotland was characterised by its variability and lack of resources. In part this was due to the lack of support for STD provision. However, it was also a function of the lack of consensus within Scottish governance and medical community with respect to the degree to which tracing should be allowed to intrude on civil liberties. In particular the SHHD was sensitive to the degree of stigma attached to such diseases and were resistant to more interventionist policies.

Implications

We can see from the above accounts that debates existed over the liberal nature of drug misuse and STD policy at both local and national (Scottish) level. With respect to policies on drug misuse, there were those who favoured penal measures to counter addiction, and the introduction of harsher prison sentences. In contrast, there were those who favoured liberal forms of addressing the drug misuse problem, which included maintenance therapy and the adoption of a multi-disciplinary approach which sought to reduce drug misuse by offering a flexible range of treatments tailored to individual needs and the avoidance of relapse.

Similarly, within STD policy-making, disagreement existed amongst Scottish Office departments and pressure groups over appropriate types of treatment and sex education initiatives. Scottish churches were strongly in favour of a sex education programme that was set within a context of Christian values and morals and their

views constituted a powerful constraint on the type of sex education policy to be implemented in schools. In contrast, some venereologists and contact tracers favoured more liberal advice about condom use. Tensions over sex education were also evident within government departments, especially between the SED, the SHHD and the SHEU over their degree of involvement in what was seen to be a politically sensitive issue.

These tensions often reflected wider concerns about the need to control immoral behaviour, particularly in young people who were perceived as promiscuous or feckless and undeserving of treatment. Such perceptions contributed to the lack of Scottish Office support and, as will be shown in the following chapters, had implications for the policy response to AIDS.

PART ONE – THE EARLY RESPONSE TO AIDS IN EDINBURGH – 1982 – 1985

Part One of this thesis deals with the response to AIDS in the early years of the epidemic between 1982 and 1985. Chapter 3 concentrates on the initial response by the medical and gay communities, between 1982 and 1984, and demonstrates the way in which their work soon became a joint effort in an attempt to curb the spread of the disease throughout the City. It shows that by the end of 1984, tensions arose within the gay community over discriminatory policy measures adopted to secure blood supplies in Scotland. Chapter 4 focuses on 1985 and explores the increasing response to AIDS from the Scottish Office, particularly with respect to notification, testing, guidelines for educational establishments and the discovery of Human T-cell Lymphotropic Virus-III (HTLV-III) amongst drug misusers. This Chapter also analyses the interface not only between Edinburgh and Scotland but between Scotland and the rest of the UK, emphasising the importance of Scottish factors in policy divergences.

CHAPTER 3 - THE INITIAL RESPONSE TO AIDS BY THE MEDICAL AND GAY COMMUNITIES – 1982 - 1984

This chapter will focus upon the work of some of the early pioneers, who responded to the threat of AIDS in Edinburgh between 1982-1984. Attention will be paid to members of local medical and gay communities in order to show how their independent concerns led to the formation of the first voluntary AIDS group in Scotland. By the end of 1984, the concerns about Scotland's blood supplies led to more stringent policy measures to secure blood supplies and created tensions within the gay community.

Early Perceptions of AIDS

One of the first people from Edinburgh to respond to AIDS as a potential threat to the people of the City was Dr Sandy McMillan, Consultant Venereologist at the Department of Genito-Urinary Medicine (GUM) at the Royal Infirmary of Edinburgh. McMillan took a trip to New York in early 1982 to attend a conference on sexually transmitted infections and Gay Related Immune Deficiency (GRID), the forerunner to what subsequently became known as AIDS.¹ There, he witnessed at first hand the devastating effects of the disease on the local homosexual community. The epidemiological evidence in the USA suggested that the majority of cases were confined to homosexual men and strong links were drawn between AIDS and the lifestyles of these men, particularly the use of recreational drugs such as

¹ *Personal Communication* with Dr A. McMillan and talk given by him at, The George Bath Memorial Lecture – 'Looking Back' – Tuesday 10 May 2005.

amphetamines and inhalational nitrites (also known as ‘poppers’), and promiscuous sex.

McMillan subsequently reported on his USA trip to the Scottish Branch of the Society for the Study of Venereal Diseases and it was agreed that, since there were currently no cases of GRID/AIDS in Scotland, there would be no need for a co-ordinated screening programme at this stage.²

At this time, Edinburgh’s gay community perceived gay American men as the vectors of AIDS. For example, Alastair Hume, who ran a gay bar called Key West, claimed that in the early 1980s gay men would not have sex with Americans because ‘they thought if you don’t go with Americans, then it [GRID] wouldn’t come over here’.³ These accounts of the disease as a phenomenon peculiar to one geographical epidemiological group served to reinforce moral attitudes about disease. In this case, gay Scotsmen felt safe, immune and apart from the diseased ‘Other’.⁴ By distancing themselves from the perceived source of the disease they were able to make sense of their own susceptibility. As others have shown, this strategy was not just a feature of the AIDS epidemic but was located in past responses to the threat of epidemics.⁵

² Department of Genito-Urinary Medicine, Royal Infirmary of Edinburgh, Minutes of Society for the Study of Venereal Diseases (Scottish Branch), 1 October 1982.

³ Quoted in, S. Garfield, *The End of Innocence – Britain in the Time of AIDS* (London and Boston, Faber and Faber, 1995), p. 32.

⁴ S. L. Gilman, *Disease and Representation – Images of Illness from Madness to AIDS* (New York, Cornell University Press, 1988), p. 4.

⁵ C. Rosenberg, ‘Disease and Social Order in America: Perceptions and Expectations’, in E. Fee and D. M. Fox (eds), *AIDS: The Burdens of History* (Berkeley, Los Angeles, London, University of California Press, 1988), pp. 12-32; A. Brandt, *No Magic Bullet: A Social History of Venereal Disease in the United States since 1880*. Expanded Edition with new chapter on AIDS (Oxford, Oxford University Press, 1987), pp. 183-204.

By early 1983, the awareness of AIDS in the UK began to heighten. The incidence of AIDS in London had increased and the screening of a BBC Horizon Programme on AIDS in the USA, *Killer in the Village*, warned that the gay community in the UK could expect similar cases.⁶ Before long the *Lancet* and the *British Medical Journal* published letters asking GUM consultants and Dermatologists across the UK to report cases.⁷ At a conference of Scottish Venereologists, in May 1983, it was agreed that an AIDS screening programme for gay men should now be implemented.⁸

AIDS in Scotland

In the summer of 1983 two cases, where AIDS was highly suspected, had been reported to *Gay Scotland*, a bi-monthly magazine⁹. The cases had yet to be confirmed but one was known to be a gay man who had recently returned to Edinburgh from New York. Little was known about the other case except that he was based in Tayside but was not Scottish. Writing in the July/August issue of *Gay Scotland*, McMillan began to appeal to gay men to visit their local GUM clinic for regular checks. He stressed that '[n]o-one need feel they are wasting our time. Just come in and say you want an AIDS check and we will oblige'.¹⁰ In the absence of a diagnostic test at that time, identifying AIDS depended upon clinical examination and pathology reports. Clinical examination looked for signs of persistent generalized lymphadenopathy (PGL), weight loss, fever and oral thrush.¹¹

⁶ V. Berridge, *AIDS in the UK – The Making of Policy, 1981-1994* (Oxford, Oxford University Press, 1996), p. 16.

⁷ *Ibid*, p. 24.

⁸ A. McMillan, 'Doctor Appeals to Gays', *Gay Scotland*, 9 (July/August 1983), p. 10. *Gay Scotland* was a bi-monthly magazine published by the Scottish Homosexual Rights Group.

⁹ *Ibid*, p. 10.

¹⁰ *Ibid*.

¹¹ A. McMillan, The George Bath Memorial Lecture – 'Looking Back' –10 May 2005.

McMillan was known and trusted by the local gay community. In addition to his work as a Consultant Venereologist, he was the author of an advice column in the local gay press and had links with Edinburgh Gay Switchboard.¹² Aware that his advice might be interpreted as discriminatory, he stressed that, 'although by no means always the case, the larger the number of sexual partners, the greater is the risk of developing AIDS. Consider having sexual intercourse with as few different people as possible'.¹³ The extent of McMillan's personal commitment was considerable. At the request of the local gay community he attended social events, including discos, in order to disseminate information to those at risk. Describing this experience in a recent interview he claimed that, although he had given many lectures to undergraduates, postgraduates and researchers, this was the most terrifying:

It was midnight on a Friday or Saturday. There was a sea of faces; the majority were young men who had been quite clearly having a good time. Most of them had quite a lot of alcohol and I thought, 'How are they going to receive me, the prophet of doom?', but in fact it was a tremendous experience. I got the message over about this infection and how it was transmitted and how people could take care.¹⁴

AIDS in the Blood

New medical evidence from the USA in 1983 suggested that AIDS could be transmitted through blood. The discovery that a number of haemophiliacs had

¹² See, for example, A. McMillan, 'The Clinic Habit', *Gay Scotland*, 7 (March/April 1983), p. 11. See also, A. McMillan, 'Recollections of HIV/AIDS in Edinburgh', (www.rememberwhen.org.uk). 'Remember When' is a project that was set up by the Living Memory Association in Edinburgh to document oral histories of the lives and achievements of Edinburgh's Lesbian, Gay, Bisexual and Transgender people, past and present.

¹³ A. McMillan, 'A Doctor's Answers', *Gay Scotland*, 9 (July/August 1983), p. 11.

¹⁴ Extract from Dr A. McMillan interview with Living Memory Association, Edinburgh, cited at the Exhibition on Stories from Lesbian, Gay, Bisexual and Transgender Edinburgh, Rainbow City, (Edinburgh City Arts Centre, 6 May to 9 July 2006).

developed AIDS there, and in Spain, pointed towards the use of American blood products, specifically Factor VIII concentrate (a clotting agent needed by sufferers to prevent blood loss) as the route of transmission.¹⁵ This was followed by media reports in the UK, which revealed that two male haemophiliacs were in hospital in London and Cardiff suspected of having AIDS after treatment with blood products.¹⁶ It was strongly suspected that the blood had come from the donations of gay men in the USA and discussions followed in the UK about the best way to safeguard blood supplies. Regional Blood Transfusion Service (BTS) Directors in the UK were divided on the issue of asking male homosexuals to refrain from donating blood. Instead they produced a general information leaflet about AIDS, explaining who was at risk.¹⁷

In Scotland, the BTS leaflet had come under attack from the local gay community, who claimed the wording was anti-gay and likely to cause panic. In a press statement the Scottish Homosexual Rights Group (SHRG) stated that the 'majority of the gay population reject any proposals for a voluntary or compulsory ban on British gays giving blood. This ... is the most panic-stricken of the many strange proposals aired in recent weeks.'¹⁸ Although the SHRG recognised that AIDS was a disease for which the homosexual population was at risk, they stressed that the blood ban and media presentations of AIDS as the 'gay plague' failed to acknowledge that heterosexuals were also carriers and sufferers of the disease. They called for the Press

¹⁵ NAS [National Archives of Scotland], HH61/1306, Minute from DHSS, 3 May 1983.

¹⁶ Berridge, *AIDS in the UK*, p. 40. See also, 'Concern over Blood Products', *Scotsman*, 2 May 1983, p. 2.

¹⁷ Berridge, *AIDS in the UK*, p. 43.

¹⁸ NAS, HH61/1306, Press Statement from Scottish Homosexual Rights Group, 21 May 1983.

and the medical profession to adopt a responsible attitude to prevent panic and a broader presentation to prevent complacency amongst the heterosexual population.¹⁹

Gay-Medical Relations

The Edinburgh BTS were also gravely concerned about the news of a suspected case of AIDS in Edinburgh and decided to take a more direct approach than other BTS's in the UK. In response, the Director of the Edinburgh and South-East Scotland BTS, Dr Brian McClelland, appealed directly to the gay community for help in preventing the spread of AIDS. At a meeting with the SHRG, Dr F. E. Boulton, the Deputy Director of Edinburgh BTS stated that 'co-operation and help are vital in containing this disease'.²⁰ This co-operation led a revised donor leaflet, which was less discriminatory, and was available in donor centres throughout Scotland and through pubs and clubs.²¹

Arguably, one of the reasons behind such a response to the threat of a suspected case of AIDS, by the Edinburgh BTS, was recent local experience of blood-borne disease. Fresh in the minds of the BTS staff was the memory of the Hepatitis B outbreak in the City in the late 1960s and early 1970s at the Renal Unit, Royal Infirmary of Edinburgh.²² The outbreak had affected not only patients but also hospital staff,

¹⁹ *Ibid.* The Scottish press were equally as guilty of presenting AIDS as a 'gay plague'. See for example, 'Scotland on Guard for 'Gay Virus'', *The Scotsman*, 3 May 1983, p. 11.

²⁰ N. Cook and D. Ogg, 'AIDS in Scotland – Mystery Virus Claims Two', *Gay Scotland* (July/August 1983), No. 9, pp. 10-11.

²¹ The first Scottish National Blood Transfusion Service message to donors about AIDS was printed in July/August 1983. A copy was printed in the July/August 1983 issue of *Gay Scotland*.

²² 'Important Events in Dialysis in Edinburgh – The Edinburgh Hepatitis Outbreak', Renal Unit of Edinburgh's Royal Infirmary website, <http://renux.dmed.ed.ac.uk/EdREN>; Personal Communication with Helen Zealley, former Chief Area Medical Officer in Lothian, 1988-1997. See also Colin Douglas' novel, *The Houseman's Tale* (London, Hutchinson, 1975), which is based loosely on the outbreak of Hepatitis in Edinburgh during this time.

including a laboratory technician from the BTS.²³ One health worker recalled that Hepatitis B wiped out a 'section of the health caring profession and that sort of legacy, a memory, is still in Edinburgh and you can't ever get rid of it'.²⁴

In this context, the BTS, at the request of Dr Peng Lee Yap, who had recently been appointed Consultant Immunologist there, received information on AIDS from Dr Ray Brettle, who had been on sabbatical in the USA during 1982-83 and was given the opportunity of examining his first few cases of AIDS.²⁵ Brettle, a Consultant in Infectious Diseases at the City Hospital, recalled that the 'Blood Transfusion people were very worried' about AIDS.²⁶ Like McMillan, Brettle used his newfound experience in order to spread information and knowledge locally, giving talks to hospital staff upon his return. Not all responses were positive however. Some staff thought he 'was mad and a lot of [his] talks met with indifference'.²⁷

Scottish AIDS Monitor is Born

At a joint meeting between the gay and medical communities on the issue of blood donation, an agreement was reached to set up a monitoring group in order to inform gays in Scotland about the risks of AIDS. A SHRG member announced in *Gay Scotland* that, 'Scotland was the only place in Britain where the gay community had

²³ A. H. B. Masson, *History of the Blood Transfusion Service in Edinburgh* (Edinburgh & S. E. Scotland Blood Transfusion Service, n.d.) p. 87. See also, Garfield, *The End of Innocence*, p. 92; and C. Douglas' novel on the outbreak.

²⁴ LHSA [Lothian Health Services Archive], EUL [Edinburgh University Library], GD24, C6, D1 (10), Draft Document by C. Bennett, 'AIDS in Lothian Case Study', 1989.

²⁵ A. Richardson, George Bath Memorial Lecture – 'Looking Back', 10 May 2005. During the period 1983-1986 I was employed as Dr Yap's personal secretary after his appointment as Consultant Immunologist. I remember clearly that one of my first tasks was to scan the Current Contents booklet every Monday morning to take notes and copy any articles on AIDS.

²⁶ Quoted in Garfield, *End of Innocence*, p. 93.

²⁷ *Ibid.*

been taken fully into the confidence of the medical profession ... and in return we [SHRG] are being given a good deal of say in how the issue is to be presented to the public'.²⁸ The monitoring group became known as Scottish AIDS Monitor (SAM) and was managed by four gay men, all of whom were members of the SHRG. Nigel Cook was an accountant, Edward McGough had a nursing background and was managing a nursing home at the time, Derek Ogg was a lawyer and Simon Taylor was a writer.²⁹ NHS doctors from Edinburgh BTS and McMillan also advised SAM. An article on the formation of SAM in the September/October 1983 issue of *Gay Scotland* stated that it 'was believed to be the first watchdog body in the United Kingdom set up with the co-operation of medical professionals working in the NHS'.³⁰

In this respect SAM was different from its counterpart in London, the Terrence Higgins Trust (THT). The THT had been established a year earlier in response to the death of Terry Higgins, a gay man from London.³¹ Known initially as the Terry Higgins Trust this was managed by a group of 'rough and ready' East End boys who raised money for medical research.³² A year later it had been taken over by a group of middle class professional homosexual men, who began to concentrate their efforts upon education, care and influencing government policy. By this time, the THT did have medical representation but this was a representative from the Gay Medical Association.

²⁸ *Ibid.*

²⁹ Personal Communication with Maureen Moore, former Chief Executive of SAM from 1983-1995. According to Edward McGough, Derek Ogg had the idea for setting up SAM. See, 'Edward McGough interview by Anne Landsburgh, 6 April 2005', Memories of Edinburgh – Remember When Project – (see online www.rememberwhen.org.uk).

³⁰ 'Scotland Gets AIDS Monitor', *Gay Scotland*, 10 (September/October 1983), p. 10.

³¹ Berridge, *AIDS in the UK*, pp. 15-6; Z. Schramm-Evans, 'Responses to AIDS, 1986-1987', in P. Aggleton, P. Davies and G. Hart (eds) *AIDS – Individual, Cultural and Policy Dimensions* (London, Falmer Press, 1990), pp. 221-32.

³² Berridge, *AIDS in the UK*, p. 16.

One of SAM's co-ordinators told *Gay Scotland* that its purpose was to 'collect, collate and disseminate accurate information on the medical condition known as AIDS'.³³ The article went on to explain that SAM's intentions were to publish regular bulletins updating the gay community with accurate information on symptoms, fundraising events, and research. It was also recorded that Dr Ann Smith of the BTS believed that SAM was 'desperately needed to combat the rumour and misinformation being spread'.³⁴ In addition, the article mentioned that medical consultants in blood transfusion had agreed to participate in an informal medical advisory group to ensure that any medical information that SAM provided would be accurate and up-to-date.³⁵

It was 1984 before SAM produced its first official information leaflet. 'Facts about AIDS' was cautious at this stage about drawing links between promiscuity and AIDS and advising gay men to reduce their sexual partners. The leaflet reported epidemiological evidence which showed that 70% of USA victims of AIDS were homosexuals, and 25 out of 33 cases of AIDS reported in the UK had occurred in gay men. It went on to say that neither SAM nor anyone else knew what caused AIDS. No advice was given with regard to reducing the risk of AIDS by altering sexual habit or reducing sexual activity. Instead, it was stated that:

[T]his is a fact sheet and we don't give out advice about something like this which we know so little about. Our medical advisers however ask you to try to be more aware of your health, take sensible hygiene precautions, keep to a decent diet and don't be slow to visit the clinic if you're worried about symptoms.³⁶

³³ 'Scotland Gets AIDS Monitor', *Gay Scotland*, 10 (September/October 1983), p. 10.

³⁴ *Ibid.*

³⁵ *Ibid.*

³⁶ NAS, GD467/1/2/17, 'A.I.D.S. – The Facts', published by Scottish AIDS Monitor, 1984.

Most of SAM's funding came from the gay community at this time. Collection boxes were distributed around gay bars and fundraising events such as discos provided the money for printing bulletins and information leaflets. In Edinburgh, some fundraising events took place at Fire Island Disco and Key West Bar (both gay venues). One gay activist recalled these days:

I remember we did a benefit concert, sort of late night show to raise money for Scottish AIDS Monitor as part of the Festival and we got various comedians and performers who were working on the Festival to come that night and make a contribution, do an act; one of them was Julian Clary who at that time was known as 'The Joan Collins Fan Club and Fanny the Wonder Dog.' I was the host, the MC. I introduced all the acts and tried to be funny and informative about the work of Scottish AIDS Monitor, trying to make jokes about AIDS for the first time, thinking 'I'm on a hiding to nothing here' but we managed somehow.³⁷

The owner of the Key West Bar, Alistair Hume, also showed his support and donated kegs of lager that were sold at discount with the proceeds given to SAM. Hume told SAM he would do everything he could to help them, since 'the gay scene ha[d] to stick together on this one'.³⁸

Due to the lack of funds for a permanent office, SAM was given space in the nursing home managed by Edward McGough, just outside Edinburgh at Lasswade. Here, the Chief Executive of SAM (who had previously worked with McGough in the nursing home) helped set up two conferences in Edinburgh and Glasgow in 1984.³⁹ The aim of the conferences was to bring together professionals with an interest in AIDS, in

³⁷ J. Ramage, 'Recollections of HIV/AIDS Activism During the Early 1980s in Edinburgh', (see, www.rememberwhen.org.uk).

³⁸ 'Scotland Gets AIDS Monitor', *Gay Scotland*, 10 (September/October 1983), p. 10.

³⁹ Personal Communication with Maureen Moore, former Chief Executive of SAM, 1983-1995.

order to raise awareness at the local level. Two sufferers from AIDS were invited to speak about what it was like to have the disease.⁴⁰

While SAM and other members of the SHRG did their best to allay fears and unnecessary panic in the gay press, the Scottish popular press continued to present the disease as a 'gay-plague' and reinforce notions of homophobia. For example, the *Scottish Daily Record*, in 1984 depicted AIDS as a disease that was 'rampant amongst homosexuals'.⁴¹ The Secretary of the SHRG replied to its Editor claiming that their portrayal was not only stigmatising, but also misleading, since AIDS was known to exist among heterosexual men and women in Central Africa.⁴² By the summer of 1984, the SHRG were faced with more discrimination against homosexuals, only this time it came from the medical community who introduced further measures to ensure that Scotland's blood supply was safe from AIDS.

AIDS and Scottish Blood Products

In August 1984 the SHHD had been informed by the SNBTS that a Scottish resident haemophiliac had contracted AIDS.⁴³ It was thought that Scottish blood products were not implicated because the patient had recently moved to Scotland, having previously been treated in England, where imported Factor VIII had been used. Nonetheless, Scottish civil servants and the SNBTS remained concerned that the Press

⁴⁰ *Ibid.* These two people were founder members of Body Positive, a self-help group for seropositive men based mainly in and around London. The first was Jonathan Grimshaw, a TV Production Manager, who had been diagnosed seropositive in 1984 and who had provided the initial premises for Body Positive in his flat. The other was Peter Randall, a civil servant, also diagnosed positive around the same time. See also, Berridge, *AIDS in the UK*, p. 22.

⁴¹ 'Mystery over Victim of Gay Plague', *Scottish Daily Record*, 17 February 1984.

⁴² NAS, GD 467/1/2/17, Letter, T. Shearer to Editor, *Scottish Daily Record*, 18 February 1984.

⁴³ NAS, HH/1306, Minute, J. G. Davies to J. MacKay, 29 August 1984.

might get hold of the story and harm the SNBTS's reputation of AIDS-free Scottish blood products.⁴⁴ Having recently become self-sufficient in blood supplies there was a lot at stake for the SNBTS. There was a concern that blood donations would diminish, because of irrational fears that even this risk-free process caused a danger of contracting AIDS. SNBTS leaflets reminded donors that there was no risk of AIDS from donating blood. Scotland relied heavily on the generosity of voluntary blood donations from its residents.

Furthermore, the SNBTS may have feared that media exposure would lead to a demand for blood products to be heat-treated. Although the AIDS virus had been discovered by this stage, widespread testing was not yet commonplace and heat treatment was an option to ensure virus-free blood.⁴⁵ As Berridge has pointed out, heat treatment was an expensive process.⁴⁶

The confirmed presence of AIDS in Scotland, regardless of its origin, did appear to give the SNBTS cause to strengthen their efforts to dissuade those in the AIDS high-risk groups not to give blood, particularly the gay community. A revised SNBTS blood donor leaflet was produced at the end of August 1984, which stated that all 'sexually active homosexual men' should not donate blood, whereas only 'men who [had] multiple partners of the same sex', were advised against donating in the 1983

⁴⁴ *Ibid.*

⁴⁵ In 1983 and 1984 the virus associated with AIDS was discovered in France and the United States, respectively. Luc Montagnier and his team referred to it as LAV (lymphadenopathy-associated-virus). Robert Gallo and his team referred to the virus as Human T-cell Lymphotropic Virus-III (HTLV-III). Both terms were used independently, interchangeably or even together at the time. In Scotland and the UK there was a preference for HTLV-III. However, it was later shown that both were identical. Around 1985/86, by agreement, the virus associated with AIDS came to be known as HIV (Human Immunodeficiency Virus). For more details see M. D. Grmek, *History of AIDS: Emergency and Origin of a Modern Pandemic* (Princeton New Jersey, Princeton University Press, 1990), Chs 6-7.

⁴⁶ Berridge, *AIDS in the UK*, p. 46.

original Edinburgh BTS version.⁴⁷ The National BTS started to revise its leaflets in a similar way from 1985.⁴⁸ Practising homosexual and bisexual men were asked to refrain from donating blood by January 1985.

In summary, it could be argued that the perceived risk to Scottish blood products generated fear and panic amongst blood transfusion personnel which led to a policy that was not only informed by epidemiological risk groups, but conflated with moral judgements based on who a person was rather than what lifestyle they led. Homosexuality and promiscuity came to be viewed as one and the same thing when Scottish blood products appeared to be under threat. All homosexuals who were sexually active were now considered to be the vectors of disease.

Divisions within the Gay Community

The change in blood donation policy appears to have led to divisions over the issue within the gay community, especially between SHRG and SAM. For example, the Editor of SHRG's magazine, *Gay Scotland*, wrote of feeling oppressed by the 'new blanket advice to gay men to cease donating their eyes, their kidneys and their blood'.⁴⁹ He went on to say, 'We [the gay community] should not be asked to shoulder this new pariah burden, having only relatively recently thrown off the stigma of being gay.'⁵⁰ In another issue of *Gay Scotland*, one of its readers warned against 'creeping medicalization' in Scotland, especially with respect to medical opinions on

⁴⁷ For a copy of the 1984 leaflet see NAS, HH61/1307. This leaflet was sent to all donors who received mailed reminders to give blood.

⁴⁸ Berridge, *AIDS in the UK*, p. 48.

⁴⁹ I. Dunn, 'Your Body is Not Unclean', *Gay Scotland*, 19 (March/April, 1985), p. 4.

⁵⁰ *Ibid.*

gay lifestyles.⁵¹ As David Altman points out, there is a history of suspicion amongst the gay population, who saw the medicalization of homosexuality as an attempt to control it.⁵²

SAM, however, continued to collaborate with the medical profession in Edinburgh. It also took a more direct stance in a new information leaflet produced in late 1984 which told the gay community that '[i]f you have a very large number of sexual partners...we advise that for the meantime you cut down the number of *different* contacts you have'.⁵³ Although SAM would have been aware of the discovery of the AIDS virus, they were also aware at this time that a sexually active gay male had been diagnosed as suffering from 'prodromal AIDS, sometimes call 'pre-AIDS'... The patient resided in Edinburgh and he [was] treated on an out-patient basis at the Edinburgh Royal Infirmary'.⁵⁴ This could well have influenced their decision to offer advice on how to reduce the risk of AIDS. As with the revised BTS leaflet, this change in SAM policy also demonstrates the ways in which local epidemiology and the perception of disease in relation to one's own environment or locality can generate more specific advice on prevention measures.

HTLV-III in Edinburgh

These measures to ensure the safety of blood supplies proved to be in vain as further information came to light by the end of 1984, indicating that Scottish blood products were no longer free from the newly-discovered AIDS virus, HTLV-III. In the autumn

⁵¹ P. Brownsey, 'Creeping Medicalization', *Gay Scotland*, 18 (January/February, 1985), p. 34.

⁵² D. Altman, *AIDS and the New Puritanism* (London and Sydney, Pluto Press, 1986), pp. 40-1.

⁵³ D. Ogg and N. Cook, 'Scottish AIDS Monitor', *Gay Scotland*, 17 (November/December 1984), p. 5.

⁵⁴ *Ibid.*

of 1984, a virologist at the Middlesex Hospital developed a British serological test to detect previous exposure to the virus, for the purposes of research on haemophiliacs across the UK. The findings showed that around a third of haemophiliacs who had taken Factor VIII had antibodies to the virus.⁵⁵ Most of these haemophiliacs were located in England and Wales. However, around 40 haemophiliacs in Scotland were found to be infected.⁵⁶ Sixteen haemophiliacs had received Factor VIII from a Scottish donor who was 'thought to have been sharing accommodation in Glasgow with a number of other men and to have given blood despite the known contraindications'.⁵⁷ In Edinburgh it was known that around 20 haemophiliac patients had antibodies to HTLV-III.⁵⁸

Soon after the discovery of HTLV-III the SNBTS requested a signed statement from blood donors claiming that they were not in any of the 'at risk' categories for contracting AIDS and began to heat-treat all its Scottish produced Factor VIII to ensure that haemophiliacs in Scotland were no longer at risk.⁵⁹

Meanwhile, the Scottish press, in collaboration with BTS representatives, attempted to present a picture of Scotland as an AIDS-free country. For example, on 28 November 1984, the *Edinburgh Evening News* told its readers that not one person had contracted AIDS in Scotland as a result of blood transfusions or treatment with preparations made from Scottish blood. Professor Ronald H. Girdwood, President of

⁵⁵ Berridge, *AIDS in the UK*, p. 46.

⁵⁶ NAS, HH61/1306, Minute, J. G. Davies to J. MacKay, 5 December 1984.

⁵⁷ *Ibid.*

⁵⁸ LHSA, EUL, GD24, C5, D3, (2.1.1.), Lothian AIDS Advisory Group Agendas and Minutes, Minute of 7 November 1984. See also, C. A. Ludlam, C. M. Steel, R. Cheingsong-Popov, D. B. L. McClelland, J. Tucker, R. S. Tedder, R. A. Weiss, I. Philp and R. J. Prescott, 'Human T-Lymphotropic Virus Type III (HTLV-III) Infection in Seronegative Haemophiliacs after transfusion of Factor VIII', *The Lancet*, 326 (1985), pp. 233-6.

⁵⁹ NAS, HH61/1306, Minute, J. G. Davies to J. MacKay, 5 December 1984.

the Royal College of Physicians of Edinburgh and Chairman of the Scottish National Blood Transfusion Association, said that the people in Scotland had nothing to ‘worry about’.⁶⁰ He attributed the lack of AIDS in Scotland to its strong tradition of voluntary blood donations, which had made it self-sufficient and not reliant upon commercial American blood products. Girdwood’s statement implied that this act of altruism was the cornerstone to safe supplies of blood and blood products. Masson’s history of the BTS in Edinburgh also suggests that its tradition of a voluntary blood donation service, as set up by Jack Copland in the late 1920s, was an important factor in achieving self-sufficiency.⁶¹ In this context, Girdwood supported the view taken by Titmuss who originally argued that blood given for altruistic reasons was purer than that given for money.⁶²

In a similar vein, another article in the *Edinburgh Evening News* stated that Scotland’s voluntarism ‘keeps [blood] safe’, unlike America’s commercialism where ‘dollars come first’.⁶³ Dr John Cash, National Medical Director of the SNBTS also pointed out in this article that ‘the Scottish Blood Transfusion Service’s Fractionation Centre in Edinburgh [was] the most up-to-date in Europe and [was] one of the foremost in the world’.⁶⁴ As Berridge has shown, the same distinctions between ‘good’ and ‘bad’ blood were made in England and Wales, where both NHS blood products and

⁶⁰ J. Vass, ‘“Good Scottish Blood” Lessens the Risk of Disease’, *Edinburgh Evening News*, 28 November 1984, p. 8. Although the CSA had taken over responsibility for the SNBTS a separate body known as the Edinburgh and South East Scotland Blood Transfusion Association operated as a voluntary body with a committee that included donors, donor organisers, representatives from the community and the medical profession to ‘promote the interests of the voluntary donors of blood and the voluntary helpers and to encourage and support the Blood Transfusion Service in this and other Regions of Scotland’, See, A. H. B. Masson, *History of the Blood Transfusion Service in Edinburgh*, [n.d.], pp. 88-9.

⁶¹ Masson, p. 98.

⁶² R. Titmuss, *The Gift Relationship: From Human Blood to Social Policy* (New York, Vintage Books, 1971).

⁶³ J. Vass, ‘Where Blood is Big Business’, *Edinburgh Evening News*, 29 November 1984, p. 10.

⁶⁴ *Ibid.*

imported blood products were used. Commercial blood products were heat-treated from the end of 1984, although the NHS heat-treated product was not available until mid-1985. This presented a dilemma for some haematologists, in the interim, about which product was the safest to use.⁶⁵

Interestingly, no mention was made in the above articles of the potential cases of AIDS in Scotland, amongst those who had recently contracted the virus. It was estimated at the time that around 10% of HTLV-III people were likely to develop AIDS.⁶⁶ Commenting on these articles, the SHHD felt that their general tenor gave ‘Scotland a somewhat cleaner bill of health than [was known] to be justified’.⁶⁷ However, it did not want to make a press statement until the Directors of Scottish Haemophilia Centres had resolved ‘the very difficult ethical problem of what action to take with regard to their patients’.⁶⁸

We can see from the above evidence that between 1982 and 1984 much of the response to AIDS was formed by the gay and medical communities in Edinburgh, rather than the SHHD. This pattern is similar to the UK response to AIDS during the early 1980s as described by Berridge. A new ‘policy community’ emerged made up of gay groups, scientists and doctors who formed alliances around AIDS and who started to develop policies from ‘below’, at the local level.⁶⁹

The Edinburgh response to AIDS had brought close relations between the gay and medical communities, leading to the creation of SAM and the adoption of a blood

⁶⁵ See, Berridge, *AIDS in the UK*, pp. 46-7.

⁶⁶ NAS, HH61/1306, Minute, J. G. Davies to J. MacKay, 5 December 1984.

⁶⁷ *Ibid.*

⁶⁸ *Ibid.*

⁶⁹ Berridge, *AIDS in the UK*, p. 13.

donation policy that was less discriminatory. However, as the presence of HTLV-III and AIDS reached Scotland, the new alliance was potentially at stake when further changes in donation policy, to exclude all sexually active homosexual men, were interpreted by some in the gay community as stigmatising. These measures were taken some months before the rest of the UK and reflect a history of concern relating to past experiences of epidemics such as Hepatitis B and, in the Scottish context, to concerns about maintaining self-sufficient blood supplies.

The evidence presented in this chapter on the media's role in relation to the response to AIDS makes it difficult to form any generalised judgements. The gay press played a responsible role in alerting gays to the dangers of AIDS. However, the popular press (both tabloid and broadsheet papers) tended to present AIDS as a 'gay plague' well into 1984 and reinforced notions of homophobia, as did the UK press. At the same time the Scottish media also presented AIDS as a heterosexual disease, amid anxieties about blood supplies. In this context, Edinburgh's 'policy community' used the press to portray Scotland as an AIDS-free country at a period when the virus was present in the country. While the SHHD was aware of these events, they were reluctant to make any public statement to alert the general public of the dangers of AIDS for fear this would cause alarm. The next chapter will demonstrate that, by the end of 1985, the perception of the risks of AIDS in Edinburgh had changed dramatically resulting in greater intervention from statutory and government bodies.

CHAPTER 4 – THE DISCOVERY OF HTLV-III IN INTRAVENOUS DRUG MISUSERS – 1985

This chapter will focus on the response to AIDS in Edinburgh during the year 1985. In the first half of 1985 many of the measures, which subsequently came to affect Edinburgh, were shaped by national debates, particularly relating to the notification procedures for identified cases of AIDS and the testing of all blood donations for HTLV-III. In both these areas, Scotland fell in line with England and Wales, albeit reluctantly at times. By the summer of 1985, the discovery of HTLV-III amongst intravenous drug misusers prompted the need for new measures by local voluntary and statutory agencies in the City. Some of these initiatives revealed tensions between medical specialities over issues of patient confidentiality and protection of patients from stigma. These issues were also apparent at a national level, which led the Scottish Home and Health Department (SHHD) to take a direct stance, in contrast to the UK, by adopting sensitive measures over the issue of disclosure of medical information with respect to educational guidelines. At the same time, the SHHD remained reluctant to address the matter of AIDS and drug misuse, particularly the supply of needles and syringes as a means of preventing spread of infection.

AIDS as a Notifiable Disease

Notification of AIDS was one of the first issues to be raised by the Expert Advisory Group on AIDS (EAGA), established in early 1985 by Donald Acheson, Chief Medical Officer (CMO) at the Department of Health and Social Security (DHSS). Notification is a system that was used in infectious disease to secure knowledge of the

whereabouts of cases in order to prevent an epidemic. For example, the Notification of Diseases Acts in 1889 and 1899 required infectious diseases to be compulsorily reported to the medical officer of health, who had it in his power to remove and isolate sufferers.¹

Representation on the EAGA from Scotland included Dr Brian McClelland, Director of Edinburgh Blood Transfusion Service (BTS), Dr John Cash, Scottish National BTS and Dr Robert Covell, Senior Medical Officer at the SHHD. Notes of one meeting on the issue indicated that ‘there was no major arguments in favour of notification and many people were actively against it’.² At the time a number of politicians were in favour of making AIDS a notifiable disease, which would give them power to detain someone in isolation or prohibit them from donating blood, as a means of preventing transmission.³ The EAGA were against such proposals for fear that they could alienate high-risk groups in society, such as homosexual men.⁴

Covell advised the SHHD CMO, Dr John Reid, that Scotland, should follow the ‘sensible’ approach of England and Wales, which would prevent alienation, because those that were HTLV-III positive without AIDS could be just as dangerous as those with AIDS.⁵

In February 1985, the Government announced that it was not necessary at the present time to make AIDS a notifiable disease. It was felt that the current system of

¹ D. Porter and R. Porter, ‘The Enforcement of Health: The British Debate’, in E. Fee and D. M. Fox (eds), *AIDS – The Burdens of History* (Berkeley, Los Angeles and London, 1988), pp. 97-120.

² NAS [National Archives of Scotland], HH61/1306, Minute, R. G. Covell to SHHD, 4 February 1985.

³ V. Berridge, *AIDS in the UK – The Making of Policy, 1981 – 1994* (Oxford, Oxford University Press, 1996), pp. 65-6.

⁴ *Ibid.*

⁵ NAS, HH61/1306, Minute, R. G. Covell to SHHD, 4 February 1985.

surveillance run by the Communicable Disease Surveillance Centre (CDSC) was adequate in recording cases of AIDS in the UK.⁶ The equivalent in Scotland was the Communicable Diseases (Scotland) Unit (CDSU) at Ruchill Hospital in Glasgow. However, the Government extended the regulations under the Public Health (Control of Disease) Act 1984 to include AIDS. This allowed them to detain patients in hospital with AIDS who were in a highly infectious state. The SHHD were also in agreement with the Government on this matter.⁷ However, Public Health Law in Scotland was different and had no need of change, since the 'relevant provisions [were] contained in the Public health Act (Scotland) 1897 and the Health Services and Public Health Act 1968'.⁸

Testing of Blood Donations

Debates over the benefit of testing all blood donations began to emerge in early 1985, as a further means of securing safe blood supplies. The SHHD were informed that Ministers at the DHSS had agreed that, once a reliable test had become available, England and Wales would start to test all blood donations for the presence of the HTLV-III virus.⁹ The question arose at the SHHD whether Scotland should follow suit.¹⁰

One senior civil servant, Mr J. G. Davies, who had responsibility for blood transfusion services at the SHHD, believed that 'the balance of rational argument

⁶ Berridge, *AIDS in the UK*, p. 24.

⁷ NAS, HH61/1306, Minute, J. MacKay to J. G. Davies, 29 January 1985.

⁸ *Ibid*, HH61/1307, Letter, J. J. A. Reid to CAMOs, 22 March 1985.

⁹ *Ibid*, HH61/1306, A. M. MacPherson to J. G. Davies, 11 February 1985.

¹⁰ *Ibid*, J. G. Davies to G. A. Scott, 7 February 1985.

would be heavily against introducing a test on all donations'.¹¹ This view was based on a number of considerations. First, a quarter of a million blood donations a year were collected in Scotland, and only one of these had been found to contain antibodies so far. Secondly, all blood products in Scotland were being heat-treated to eliminate the virus and donors were asked to sign a statement that they did not fall into one of the 'at-risk' categories for contracting AIDS. Thirdly, if tests were to be introduced, the financial implications of testing on this scale, estimated to cost around £300,000 per annum, would need to be considered, as well as costings for follow up of those testing positive. Fourthly, consideration would need to be given to the 'inevitable' problems created by false positive tests as well as false negative tests.¹² Finally, there would be a danger that people 'at risk' of AIDS might attend donor sessions purely with the intention of discovering their HTLV-III status.¹³ Davies concluded 'that there [was] little rationality to be seen where AIDS is concerned. We seem to have reached a point where an AIDS victim cannot even be given a public funeral, presumably in case noxious vapours emanating from the coffin strike down the congregation in the middle of the service.'¹⁴

Some of his colleagues at the SHHD shared similar reservations, but all felt that if Scotland did not proceed to test all blood donations, in line with England and Wales, there would be media and public pressure to do so.¹⁵ For example, one Deputy CMO expressed the view that 'the rising tide of emotion' appeared to be taking the decision

¹¹ *Ibid.*

¹² *Ibid.*

¹³ *Ibid.*

¹⁴ *Ibid.*

¹⁵ Although there were many shared interests in matters concerning the health of the UK, each health department was run independently. The SHHD was a government department within the Scottish Office and was responsible to the Scottish Minister for Health. See, for example, J. Brotherston, 'The NHS in Scotland – 1948-1984' in G. McLachlan (ed) *Improving the Common Weal – Aspects of Scottish Health Services 1900-1984* (Edinburgh, Edinburgh University Press), pp. 103-59.

out of the SHHD's hands.¹⁶ Another colleague stated that the desire for testing was 'more a question of public presentation than a matter of medical judgement and the pressure on us to follow the English example [would] be irresistible'.¹⁷

Soon after these discussions the SHHD held talks with Dr John Cash, who was an adviser to the SHHD on blood transfusion matters.¹⁸ In a letter to John Reid, the CMO, he stated that he was in favour of testing but urged caution rather than haste because evidence suggested that commercial screening kits might produce false-positives, which could lead to considerable distress and suffering for donors and their families.¹⁹ In addition, BTS services had not yet established appropriate counselling facilities, nor the required technical back-up services to detect false-positives. Cash also stated that, if these measures were not in place, there could be a resultant decline in donors. He concluded that the NHS was committed to the introduction of HTLV-III antibody screening, but the interests of the Transfusion Services and their responsibility for maintaining the supply of blood and blood products to all patients in Scotland, needed to be considered before the test was introduced. He believed that a national screening test evaluation programme would need to be carried out in the first instance.²⁰

Cash's views were appreciated by the SHHD, but it would appear that pressure from the Scottish Health Minister, John MacKay, contributed to the decision to introduce

¹⁶ NAS, HH61/1306, Minute, G. A. Scott to J. G. Davies, 8 February 1985.

¹⁷ *Ibid*, Minute, A. M. MacPherson to J. G. Davies, 11 February 1985.

¹⁸ *Ibid*, Minute, J. G. Davies to G. A. Scott, 12 February 1985.

¹⁹ *Ibid*, J. D. Cash to J. Reid, CMO, SHHD, 12 February 1985.

²⁰ *Ibid*.

routine screening for all blood donors.²¹ MacKay had informed the SHHD that ‘we do have to keep in line or ahead of England, otherwise we would be subject to very severe criticism’.²²

By the end of summer of 1985, evaluation tests on the more reliable kits for HTLV-III screening had been completed and Regional Transfusion Services in Scotland and the UK planned to screen all blood donors by mid-October. £320,000,00 was provided by the SHHD to the SNBTS for this purpose.²³ The SHHD told Health Boards (HBs) they would have to meet their own costs for testing outwith blood donor centres. They suggested that Genito-Urinary Medicine/Sexually Transmitted Diseases (GUM/STD) Clinics had experience of dealing with patients confidentially and were therefore well placed to offer counselling and the test. The SHHD also indicated that there might be a need to provide a screening service for those who did not regard themselves as appropriate clients for GUM clinics.²⁴ In addition, HBs were expected to contribute towards the costs for some of their employees to become counsellors, by attending a course, which had been arranged by a team of experts from St Mary’s Hospital, Paddington, to take place in Edinburgh by November.²⁵

Testing in Edinburgh and the Discovery of HTLV-III in Intravenous Drug Misusers

²¹ NAS, HH61/1307, Minute, A. M. MacPherson, to J. MacKay and Secretary of State, 21 March 1985.

²² *Ibid*, Minute, J. MacKay to Secretary of State, 22 March 1985.

²³ NAS HH61/1295, Letter, J. MacKay to G. Wilson Esq, MP, House of Commons, 1 November 1985.

²⁴ LHSA [Lothian Health Services Archive], EUL [Edinburgh University Library] GD24, C5, D3, (2.1.0) Lothian AIDS Advisory Group – General, Letter, SHHD to CAMOs and CMSs, 14 August 1985.

²⁵ *Ibid*, Letter, R. G. Covell, to CAMOs, 17 October 1985.

The issue of testing was also discussed at length in Edinburgh. The provision of screening facilities had been considered by the Lothian AIDS Advisory Group (LAAG) at its first meeting.²⁶ This group had formed shortly after the discovery of the HTLV-III virus in a number of haemophiliacs in Edinburgh at the end of 1984, and comprised clinicians and scientists, mainly from the Royal Infirmary of Edinburgh (RIE), and had been initially known as the AIDS Ad Hoc Group. The group was chaired by Dr Christopher Ludlam, a haematologist. Other members included Dr Brian McClelland, Dr Ray Brett, Infectious Diseases (ID), Dr Sandy McMillan, Genito-Urinary Medicine (GUM), Dr George Bath, Community Medicine Specialist and Dr John Peutherer, a Virologist. This was the first medical group to respond to AIDS in Edinburgh and their role was to advise the Lothian Health Board (LHB) on matters relating to AIDS.

One member of the group, Peutherer, Consultant Virologist at the Department of Bacteriology, University of Edinburgh Medical School, wrote to Dr Colin Brough, Chief Administrative Medical Officer (CAMO) of the LHB on 20 November 1984, seeking support for an initiative to upgrade his laboratory, in order to process specimens from high risk patients.²⁷ Peutherer enclosed a copy of a confidential report from a meeting held on 7 November 1984 by the LAAG. All of those at the meeting agreed that it was 'essential that a diagnostic service [was] introduced as soon as possible, using the facilities available in the University Department of Bacteriology'.²⁸

²⁶ LHSA, EUL, GD24 , C5, D3, (2.1.0) Lothian AIDS Advisory Group – General – Meeting, 7 November 1984.

²⁷ *Ibid*, Letter, J. F. Peutherer to C. Brough, 20 November 1984.

²⁸ *Ibid*.

When no response was received from the LHB, a further letter was sent as a matter of urgency by the Head of the Department of Bacteriology, Professor J. G. Collee. He explained that communication with colleagues at the Middlesex Hospital had alerted them to the fact that they had 'a very worrying local problem' and needed Health Board support to proceed along the lines indicated in Dr Peutherer's letter.²⁹ In the continued absence of a reply, another letter was sent by Ludlam, who informed the CAMO that he should 'support immediately the microbiologists' initiative', otherwise confusion would surround the clinical management of patients and laboratory handling of samples.³⁰ Finally, in May 1985, some six months later, the Area Executive Group of LHB made available £2,000 to finance 1,000 tests for HTLV-III antibodies.³¹

By June 1985, Peutherer had started testing and soon discovered more shocking news which had major implications for Edinburgh and the LHB. Peutherer had decided to use a local control group to test his new screening kits. He therefore used stored serum samples from intravenous (IV) drug misusers from Edinburgh, who were being followed up by George Bath for Hepatitis B.³² The results were astonishing, because the control group were 'more positive than the patients!'.³³ In a letter to the LHB on 12 June 1985, Peutherer wrote, that '22 (35%) of 62 parenteral drug abusers, including 4 out of 21 female patients, had antibodies to the virus'.³⁴ He stressed that the 'results [had] been confirmed in other laboratories and there [was] no doubt that

²⁹ *Ibid*, Letter, J. G. Collee to C. Brough, CAMO, LHB, 21 December 1984.

³⁰ *Ibid*, Letter, C. A. Ludlam to C. Brough, 25 February 1985.

³¹ *Ibid*, Minutes of LAAG, 29 May 1985.

³² R. Brettell, The George Bath Memorial Lecture - 'Did the Band Play On?', 15 May 1996.

³³ *Ibid*.

³⁴ LHSA, EUL, GD24, C5, D3, (2.1.0) Lothian AIDS Advisory Group – General.

they [were] genuine'.³⁵ He argued that such findings had implications for the management of these patients and were likely to cause an increase in demand for a diagnostic service.³⁶ The findings now demonstrated that HTLV-III had penetrated parts of the heterosexual population in Edinburgh and posed a threat to the wider public.

Health Education

Soon after Peutherer's results were revealed, a local response to the problem of HTLV-III positive drug misusers was initiated by the voluntary sector and the LHB. The voluntary sector was quick to respond to the news of the connection between HTLV-III and drug misuse. Scottish AIDS Monitor (SAM) was at the forefront of this response. As a primary disseminator of information and advice to the homosexual community in Edinburgh, SAM had already previously proved itself to be a well-organised and professional body, and had by now achieved Trust status from the Inland Revenue, formally rendering it a Charity for tax purposes.³⁷

By the middle of 1985, SAM proposed to produce a new leaflet aimed at the main 'at risk' groups, which now included drug misusers and haemophiliacs. In order to fund their proposal, a grant application was submitted to the SHHD. McClelland had promised 'his support without hesitation' for any application by SAM for grant aid to help its welfare and education products.³⁸ By July 1985, SAM had been awarded a grant of £7,000 from the SHHD, to 'install a telephone advice line, provide and equip

³⁵ *Ibid.*

³⁶ *Ibid.* See also, J. F. Peutherer, E. Edmond, P. Simmonds, J. D. Dickson and G. E. Bath, 'HTLV-III Antibody in Edinburgh Drug Addicts', *The Lancet*, 326 (1985), pp. 1129-30.

³⁷ D. Ogg, 'AIDS Update', *Gay Scotland*, 19 (March/April 1985), p. 5.

³⁸ *Ibid.*

an office, hire a part-time secretary and to print further education and advice leaflets about the AIDS-related virus, its effects and its avoidance'.³⁹ An announcement of the grant in *Gay Scotland* claimed it was the largest amount ever awarded to a gay organisation in Scotland.⁴⁰

With the help of the grant SAM produced an information leaflet in 1985, highlighting those groups at risk. Drug misusers were advised to stop sharing needles and gay men were told that the safest way to reduce the risk of AIDS was to refrain from anal intercourse.⁴¹ Soon after, in collaboration with some of Edinburgh's drug projects, SAM produced a leaflet targeted specifically at drug misusers. The leaflet advised drug misusers not to share needles with anyone, to keep their equipment clean, to avoid anal sex and to always use a condom.⁴²

The SHHD had been reluctant to engage directly in AIDS education at this stage, due to fears that their advice would be construed as condoning immoral behaviour. This reluctance was also reflected in their input to health educational measures introduced at the national level.⁴³ For example, during this period the Health Education Council (HEC) began to develop a leaflet on the risks of AIDS and invited comments from health departments. The SHHD were reluctant to get involved. One civil servant believed that it should have been possible to provide a modest payment direct to the Terrence Higgins Trust (THT) to support their educational endeavours.⁴⁴ It was also

³⁹ 'SAM Gets £7000 from George Younger', *Gay Scotland*, 23 (September/October 1985), p. 3.

⁴⁰ *Ibid.*

⁴¹ See, 'AIDS Is, AIDS Isn't'. A copy can be found in NAS, HH61/1248.

⁴² See, 'Advice and Information for Drug Users and their Sexual Partners'. A copy can be found in NAS, HH61/1248.

⁴³ NAS, HH61/1306, DHSS – 'Acquired Immune Deficiency Syndrome (AIDS): Health Education', 9 August 1984.

⁴⁴ *Ibid.*, Minute, G.A. Scott to E. C. G. Craghill, 22 August 1984.

considered that there was no need for a separate leaflet by the Scottish Health Education Group (SHEG) because the gay community probably ‘knew more about AIDS than the leaflet would tell them’.⁴⁵ Rather, SHEG could adapt the HEC leaflet with appropriate Scottish references.⁴⁶ However, it is interesting to note that SHHD does not appear to have consulted SHEG directly on the matter, suggesting an underlying concern to restrict its activities, already evident over issues of sex education and family planning.⁴⁷

Interim Guidelines for the Care and Accommodation of Patients with AIDS

The LHB responded quickly to the increasing incidence of HTLV-III and the connection with drug misuse. Interim guidelines on the care and treatment of patients with AIDS, which had been produced by the LAAG in June 1985, were distributed. These guidelines appear to have put greater emphasis on the need to protect staff rather than issues of confidentiality and the need for protection from stigma of patients. The LAAG had agreed that precautions equivalent to protection against Hepatitis B were applicable to AIDS, due to the uncertainty over the way in which the virus could be spread and how infectious it was.⁴⁸ At this time, it was known that the virus could be contracted from the blood or semen of an infected person and that there was no evidence to suggest that it could be transmitted through saliva. Thus, it was recommended in the guidelines that patients with AIDS should be:

⁴⁵ *Ibid.*

⁴⁶ *Ibid.* Minute, E. C. G. Craghill to J. G. Davies, Drs Prentice and McIntyre, 16 August 1984.

⁴⁷ R. Davidson and G. Davis, ‘This Thorniest of Problems’: School Sex Education Policy in Scotland 1939-80’, *Scottish Historical Review* 84 (2005), pp. 221-46.

⁴⁸ LHSA, EUL, GD24, C5, D3, (2.1.0) Lothian AIDS Advisory Group – General, Document, ‘Interim Guidelines for the Care and Accommodation of Patients with Acquired Immune Deficiency Syndrome (AIDS)’, June 1985.

accommodated in a single cubicle to reduce their own exposure to infection as well as minimising the risk of infection to others ... If the patient is need[ed] to be placed on a commode or a bedpan, the nurse assisting should wear a plastic apron over her uniform and use gloves. In the event of venepuncture or other invasive procedures being required, they should be carried out as described in the HAG Guidelines for similar procedures undertaken on hepatitis B surface antigen positive patients.⁴⁹

While uncertainty played a role in the decision to take a cautious approach, staff would also have been concerned given Edinburgh's history of fatality amongst hospital workers during the Hepatitis B epidemic a decade before.⁵⁰

Similar cautionary measures were recommended for patients considered to be 'others at risk' of AIDS, especially when venepuncture or invasive procedures required to be carried out. Patients in the 'other' category fell into six groups. These were patients diagnosed or suspected as having AIDS; patients diagnosed or suspected as having AIDS related complex (ARC); patients confirmed as having HTLV-III antibody in their blood; sexual contacts of AIDS cases, ARC cases or those with HTLV-III antibody in their blood; recipients of blood clotting factor concentrates, (e.g. factor VIII or factor IX); parenteral drug abusers.⁵¹ In the light of Peutherer's findings all intravenous drug misusers had come to be seen as the new vectors of disease. The guidelines stated that:

Parenteral drug abusers are included as a group because of tentative evidence that in Lothian, unlike in some other parts of the U.K., this group is more likely to carry the virus.⁵²

⁴⁹ *Ibid.*

⁵⁰ See also, Chapter 3.

⁵¹ LHSA, EUL, GD24, C5, D3, (2.1.0) Lothian AIDS Advisory Group – General, Document, 'Interim Guidelines for the Care and Accommodation of Patients with Acquired Immune Deficiency Syndrome (AIDS)', June 1985, p. 2.

⁵² *Ibid.*

By the time the LAAG guidelines had been distributed to hospital departments, some members of the medical profession began to raise concerns over their potential to stigmatise certain patients. One consultant haematologist felt that the guidelines were over-cautious with respect to some patients categorised as ‘others at risk’. The case was cited of an 85 year-old lady who had been admitted to hospital with bleeding and had a previous medical history of treatment with heat-treated Factor-VIII. The consultant discussed her case with some members of LAAG and it was agreed that she should be nursed as ‘high risk’. However, during her stay in hospital she became ‘terribly distressed, disorientated, and depressed in isolation’.⁵³ It was at this point that the consultant decided to relax the rules, because the patient had received heat-treated Factor-VIII, which he understood rendered the virus inactive.⁵⁴ No HTLV-III test was carried out to confirm her status. Interestingly, the guidelines made no distinction between those who had received heat-treated or non heat-treated Factor VIII. Anyone who had received some form of blood clotting factor concentrate was categorised as being in a ‘high risk’ group.⁵⁵

Significantly, the same consultant appeared to be less concerned about the effects of stigma when he examined a young male intravenous drug misuser who had a history of Hepatitis B and presented with thrombocytopenia (a low blood platelet count). For someone with this history the consultant considered it necessary to ‘check his HTLV-III status in the first instance’.⁵⁶ Although the patient did turn out to be positive, both

⁵³ LHASA, EUL, GD24, C5, D3, (2.1.1) Lothian AIDS Advisory Group –Agenda and Minutes – Letter, G. Stockdill, to W. Cockburn, 6 September 1985.

⁵⁴ *Ibid.*

⁵⁵ *Ibid.* (2.1.0) Lothian AIDS Advisory Group – General, Document, ‘Interim Guidelines for the Care and Accommodation of Patients with Acquired Immune Deficiency Syndrome (AIDS)’, June 1985.

⁵⁶ *Ibid.* (2.1.1) Lothian AIDS Advisory Group –Agenda and Minutes – Letter, Dr G. Stockdill, to W. Cockburn, Chairman of the Problematic Infections Group, LHB, 6 September 1985.

of these patients had been categorised as ‘others at risk’ who had invasive procedures, and should have been treated in the same manner.

The above highlights the way in which medical perceptions of disease were and are often underpinned by a set of moral attitudes towards patient groups within a defined category, differentiating those who were considered to be ‘innocent’ victims of disease, from those who were ‘guilty’ of disease due to their immoral behaviour. As Davidson has shown, similar distinctions were made during treatment for venereal diseases.⁵⁷ In addition, Berridge argues that national guidelines as set out by the Advisory Committee on Dangerous Pathogens (ACDP), in January 1985, also reflected a degree of pressure from workers, generated by fear and uncertainty over paths of transmission of the virus.⁵⁸ These were in contrast to nursing guidelines produced around the same time that set the tone for future guidelines, such as those for doctors, anaesthetists and dentists, and placed greater emphasis on confidentiality and protection from stigma.

Open Access Clinic, City Hospital

Concerns about confidentiality and protection from stigma continued to be a source of tension in Scotland, both at the local and national level. At the local level, this was apparent in the context of plans to introduce an ‘open access’ HTLV-III screening service for those who did not perceive themselves to have an STD.⁵⁹ After a long discussion with other LAAG members a decision was made to offer access to

⁵⁷ See for example, R. Davidson, *Dangerous Liaisons: A Social History of Venereal Disease in Twentieth-Century Scotland* (Amsterdam, Rodopi, 2000) pp. 109-10.

⁵⁸ Berridge, *AIDS in the UK*, p. 59.

⁵⁹ LHSA, EUL, GD24, C5, D3, (2.1.0) Lothian AIDS Advisory Group – General, Minutes of LAAG, 11 September 1985.

screening via General Practitioners (GPs), GUM clinics and a new 'open access' clinic at the City Hospital, which would cater specifically for intravenous drug misusers.⁶⁰ The 'open access' proposal was not welcomed by all in the local medical profession. The head of GUM, Dr David Robertson at the RIE was against the proposal. He believed that the only place to provide this type of confidential screening was within GUM. In a strong letter to Dr A. F. MacLeod, Community Medicine Specialist (CMS) at the LHB, on 20 September 1985, Robertson raised his concerns about the potential harm that might follow the setting up of self-referral clinics elsewhere in the hospital service for screening of 'one sexually transmitted disease (LAV/HTLV-III/ARV infection)'.⁶¹ To support his argument, Robertson enclosed a paper, outlining his views in detail.

'Screening of Antibody to the Human AIDS-Related T-Lymphotropic Retrovirus (LAV/HTLV-III/ARV)' pointed out that homosexual or bisexual males formed the main at-risk group in the UK.⁶² Robertson considered GUM departments were the most suitable for dealing with STDs, including the AIDS virus, since they could provide the necessary skills and experience to handle confidential issues.⁶³ He also drew attention to concerns of the local gay community, which feared that results of positive tests would become known to the wrong people, and that homosexuals would face yet more stigma and discrimination. These fears had been raised in an article in *Gay Scotland*, entitled 'Don't Take that Test' by D. Ogg, S. Taylor and N. Cook.⁶⁴

⁶⁰ *Ibid.*

⁶¹ *Ibid.* Letter, D. H. H. Robertson to A. F. MacLeod, 20 September 1985.

⁶² *Ibid.* Document, 'Screening of Antibody to the Human AIDS-Related T-Lymphotropic Retrovirus (LAV/HTLV-III/ARV)'.

⁶³ *Ibid.*

⁶⁴ D. Ogg, S. Taylor and N. Cook, 'Don't Take That Test', *Gay Scotland*, 20 (May/June 1985), p. 4.

The article warned that public hysteria might lead to legislation insisting on disclosure of HTLV-III positive results, thus jeopardising gay employment and life insurance.

Robertson viewed his department as the only one where 'self referral' ought to be promoted by the LHB.⁶⁵ He believed that haemophiliacs with HTLV-III infection might be better looked after by haematologists, while intravenous drug misusers could be cared for by several disciplines, but their GP might best carry out screening.⁶⁶ For Robertson this was an opportunity to rejuvenate an already chronically under-resourced department.⁶⁷ However, in the event the LHB saw the need for alternative arrangements, particularly in light of the evidence of HTLV-III amongst drug misusers, and subsequently agreed that proposals to set up a separate clinic at the City Hospital should be continued.

Ray Brettle and Brian McClelland, began to draw up plans for an 'open access' screening clinic at the City Hospital. Brettle provided a service for intravenous drug users there, especially those with Hepatitis B infection. The intention was to combine clinical and research work. An approach was made to the SHHD's Chief Scientists' Office (CSO), who agreed to fund the service for a period of six months', after which the LHB agreed to take over.⁶⁸ The new 'open access' clinic at the City Hospital began on 16 October 1985 to coincide with the start of testing of all blood donations. The research carried out there produced similar results to Peutherer's study: high

⁶⁵ LHSA, EUL, GD24, C5, D3, (2.1.0) Lothian AIDS Advisory Group – General, Document, 'Screening of Antibody to the Human AIDS-Related T-Lymphotropic Retrovirus (LAV/HTLV-III/ARV)'.

⁶⁶ *Ibid.*

⁶⁷ See for example, Chapter 2. Roger Davidson's work on STDs in Scotland indicates that, by 1985, GUM services had suffered a long history of low status within the medical profession.

⁶⁸ LHSA, EUL, GD24, C5, D3, (2.1.0) Lothian AIDS Advisory Group – General, Minutes of LAAG, 9 October 1985.

infectivity rates amongst intravenous drug users who shared contaminated needles. Around 50% of the drug users attending the clinic were found to be infected with HTLV-III.⁶⁹

Educational Guidelines

The issue of medical confidentiality also raised tensions at the national level, especially within the Scottish Office, in the context of guidelines for educational establishments. The Scottish Education Department (SED) had recognised the need to draw up guidelines in this respect and believed that the Department of Education and Science (DES) interim UK guidelines would be appropriate, with minor amendment.⁷⁰ These guidelines had been drawn up as a matter of urgency. In Hampshire, in the summer of 1985, a number of anxious parents, whose children had been attending the same school as a haemophiliac boy infected with HTLV-III, were concerned that the boy continued to attend classes.⁷¹ Parents at the school wanted all parents and teachers to be informed about the HTLV-III status of school children. The DES felt strongly that at least all teachers should be informed, while the DHSS believed that only the head teacher should be informed in the strictest confidence.

The case had received a great deal of media coverage and the public were told on British television by Norman Fowler, Secretary of State for Social Services, that advice would be issued in the near future. Subsequently, Mr Bob Dunn, Junior

⁶⁹ R. Brett, 'Did the Band Play On?', p. 5. See also, R. J. Brett, J. Davidson, S. J. Davidson, J. M. N. Gray, J. M. Inglis, J. S. Conn, G. E. Bath, J. Gillon, and D. B. L. McClelland, 'HTLV-III Antibodies in an Edinburgh Clinic', *The Lancet*, 327 (1986), p. 1099.

⁷⁰ NAS, ED39/474, Department of Education and Science, 'Education Junior Minister Mr Bob Dunn meets Representatives of the Haemophilia Society', 1 October 1985.

⁷¹ Berridge, *AIDS in the UK*, p. 57.

Education Minister, met with representatives of the Haemophilia Society, who stated that haemophiliac children whose blood contained antibodies to HTLV-III were not a risk to other children, or to teachers or staff at schools. It was subsequently agreed that although 'medical information [was] properly regarded as confidential to the child, his parents and their medical advisers, it would be available to the head teacher, who [was] responsible for the children in the management of the school'.⁷²

However, the SHHD took the opposite view because:

there [was] a strong feeling in the medical profession in Scotland that confidential information should not be passed on to head teachers and that they should merely be given general hygienic advice on how all haemophiliac children should be managed, thus preventing any potential discrimination through disclosure of information on the child.⁷³

The SED was not aware of any distinctly Scottish issues but felt there was a need to reassure its education authorities by giving the same advice as in England and Wales.⁷⁴ It informed the SHHD that there would be 'considerable sensitivity about managing all haemophiliac children as if they were carrying the virus'.⁷⁵ Subsequently, the SED called an urgent meeting with two medical consultants in haemophilia (representatives from Glasgow and Edinburgh). These doctors shared the same view as the SHHD. They felt it would be in the best interests of haemophiliac children if, in the event of an accident, they were treated in the same way. They regarded it as unnecessary as well as undesirable for Scottish head teachers to be told about the HTLV-III status of a haemophiliac child in case the child

⁷² NAS, ED39/474, Department of Education and Science, 'Education Junior Minister Mr Bob Dunn meets Representatives of the Haemophilia Society', 1 October 1985.

⁷³ *Ibid*, Minute, A. M. MacPherson, to D. J. Crawley, 15 October 1985.

⁷⁴ *Ibid*, Minute, D. J. Crawley to A. M. MacPherson, 15 October 1985.

⁷⁵ *Ibid*.

was ostracised. Furthermore, they also pointed out that even the parents of the children had elected not to know in some instances.⁷⁶

The SED duly took on board this advice and subsequently sent out copies of 'AIDS: Guidance to Education Authorities' to all Directors of Education, in late 1985, as a preliminary measure.⁷⁷ This guidance differed in certain key respects from the DES interim statement. In particular, a description of how AIDS was usually transmitted was avoided and instead focus was made upon infection in haemophiliac children. The guidelines considered that these should be dealt with in the same way as any risk group and outlined precautions to be taken when suffering from a wound. The SED, supported by Her Majesty's Inspectorate of Schools, stated that medical advice in Scotland was that it was both unnecessary and undesirable for head teachers to be informed, since this would risk stigmatising identified carriers. The main message of the guidance was that there was no evidence that HTLV-III virus could be transmitted by casual contact.⁷⁸

Clearly, the above accounts over issues of confidentiality demonstrate the sense of uncertainty during this period, giving rise to tensions, panic and fear. It could be argued that in the Scottish context, there was less media pressure to have wider disclosure. However, the Scottish press began to contribute to panic and fear in other ways, by reinforcing concern about Edinburgh's HTLV-III incidence amongst drug misusers, and presenting an image of this population as the new vectors of disease. For example, Brian McClelland told a press conference that there was concern about the prevalence of the virus among drug addicts, particularly in the Edinburgh area

⁷⁶ *Ibid*, Minute, D. J. Crawley to Scottish Ministers, 22 October, 1985.

⁷⁷ *Ibid*, Letter, D. J. Crawley to Directors of Education, 24 October 1985.

⁷⁸ *Ibid*, Minute, SED to Mr Stewart, 22 October 1985.

with a risk of heterosexual spread.⁷⁹ His warning to people was to ‘choose their sexual partners very carefully’.⁸⁰

At the same time, the Scottish press also attempted to reassure the public. For example, *The Scotsman* ran a story stating that ‘Concern about AIDS Must be Contained’. Here, Brettle called for the public not to let their fears get out of hand.⁸¹

He stressed that

AIDS does not seem to be an airborne disease: it does not hop across the room like Lassa fever, for example, or measles or chickenpox. If it did, all the blood tests and surveys being done around the world would have turned up literally millions of AIDS cases by now, and they haven’t.⁸²

Meanwhile, the news of Edinburgh’s high incidence of HTLV-III spread throughout the UK and reinforced the message that everyone was at risk from AIDS. For example, a Thames Television programme, *TV Eye* entitled ‘AIDS and You’, was shown in November 1985. It told the story of Alex, a young heroin user from Edinburgh. Alex claimed that he would share a needle with anyone because he was so desperate to get the heroin into himself.⁸³

The Supply of Needles and Syringes

The SHHD remained reluctant to become directly involved in areas of policy that were too controversial. This was the case with respect to the supply of clean needles and syringes to drug misusers, in order to reduce the risk of spread of infection in

⁷⁹ B. Christie, ‘No One Yet Found With AIDS in Blood Tests’, *The Scotsman*, 8 November 1985, p. 13.

⁸⁰ *Ibid.*

⁸¹ Y. Baginsky, ‘Concern about AIDS Must be Contained’, *The Scotsman*, 28 November 1985, p. 14.

⁸² *Ibid.*

⁸³ Quoted in R. McKie, *Panic – The Story of AIDS* (Wellingborough, New York, Thorsons Publishing Group, 1986), p. 44.

Edinburgh and Scotland. For example, Derek Ogg, National Co-ordinator for SAM, wrote to the Lord Advocate, The Hon. Lord Cameron, in October 1985 asking for clarification of the legal position with regard to the supply of needles and syringes to drug addicts in Edinburgh. SAM believed that since this would stop the transmission of the virus in the high-risk groups, it would be a 'publicly responsible act' in preventing the spread of AIDS to the wider population.⁸⁴ The Crown Office sought advice from the SHHD.

By this time, the SHHD had been sufficiently concerned to conduct their own interviews with those involved with drug misusers in Edinburgh. Many workers pointed out that the growing AIDS problem was consuming all other work.⁸⁵ Some in the SHHD believed that 'one offshoot could be that the AIDS scare [would] at least discourage needle sharing or even drug abuse'.⁸⁶ Others shared Ogg's view that the availability of clean needles and syringes to intravenous drug users would be a 'major step in the prevention of spread of serious diseases such as AIDS'. This was the view of Robert Covell, who was the Senior Medical Officer responsible for infectious diseases at the SHHD.⁸⁷ Covell had close links with the Edinburgh medical profession, having recently become a member of LAAG. However, Covell also considered that implementation would not be straightforward. First, the majority of first-time users of intravenous drugs shared needles and syringes as part of the cultural experience of drug taking. Secondly, numerous problems over supply and distribution of such equipment would occur. The SHHD felt that this should remain

⁸⁴ NAS, HH61/1247, Letter, D. Ogg to Lord Advocate, 23 October 1985.

⁸⁵ *Ibid.*, HH61/1125, 'Note – AIDS', October 1985.

⁸⁶ *Ibid.*

⁸⁷ *Ibid.*, Minute, R. G. Covell to H. McBain, 6 November 1985.

under the control of the medical and pharmaceutical professions.⁸⁸ Finally, the proposal could be politically sensitive, generating accusations of ‘condoning drug abuse’.⁸⁹

In their reply to the Crown Office, the SHHD explained that there were in fact no legal restrictions with regard to the supply and demand of sterile needles and syringes.⁹⁰ The contracts of General Practitioners (GPs) with the NHS required them to provide needles and syringes for medical treatment as required. Nonetheless, the SHHD considered that although ‘the correct use of sterile needles and syringes by intravenous drug users would limit the spread of serious diseases such as AIDS, hepatitis B and septicaemia ... it [was] not acceptable to the Department [SHHD] that the NHS should allow GPs to supply such appliances whether by prescription or otherwise’ because of the implications listed above.⁹¹

By this time more bad news had emerged, which demonstrated that even more drug misusers had HTLV-III antibodies than previously indicated by Peutherer or Brettle. This came from SHHD-funded research on drug addiction in Edinburgh by Dr Roy Robertson of the West Granton Medical Group. Robertson informed the Chief Scientist’s Office at the SHHD that he had submitted an article to the *British Medical Journal* on ‘An epidemic of AIDS-Related Virus Infection Amongst Intravenous Drug Abusers in a General Practice’.⁹² The paper revealed that 51% of a sample of 164 intravenous drug abusers attending his surgery were found to have antibodies to

⁸⁸ *Ibid.*

⁸⁹ *Ibid.*

⁹⁰ *Ibid.*, Minute, H. McBain, Medical Services Department, SHHD, to A. N. MacDonald, Crown Office, 4 December 1985.

⁹¹ *Ibid.*

⁹² *Ibid.*, HH 61/1307, Letter, J.R. Robertson to J. T. Boyd, 7 December 1985.

HTLV-III. This was substantially higher than that reported elsewhere in Europe and was close to rates in New York City.⁹³ The research, which was also carried out using stored serum samples, indicated that the infection had become epidemic in late 1983 and early 1984.⁹⁴ The article suggested that there was a significant relationship between patients having positive readings and the practice of sharing a single needle and syringe at gatherings of up to 20 drug abusers in ‘shooting galleries’. The closure of the main supplier of needles and syringes in Edinburgh and increased police activity in confiscating drug injecting equipment were considered to be contributory factors in the creation of these ‘shooting galleries’.⁹⁵ These items were reported to cost more on the black market than heroin itself.⁹⁶ Some doctors in Edinburgh had already attempted to counteract police policy of confiscating equipment and adopted an unofficial service of supplying fresh needles and syringes to intravenous drug users in an effort to curb the spread of HTLV-III infection.⁹⁷ Other doctors, especially those members of the LAAG, had agreed that one of the ways in which to reduce the transmission of Hepatitis B and HTLV-III was to make needles and syringes available to injecting drug users.⁹⁸

Shortly after this news, the CMO, Dr Ian MacDonald, of the SHHD called an urgent meeting, with members of the Edinburgh medical community, many of whom were

⁹³ See also, J. R. Robertson, A. B. V. Bucknall, P. D. Welsby, J. J. K. Roberts, J. M. Inglis, J. F. Peutherer and R. P. Brett, ‘Epidemic of AIDS Related Virus (HTLV-III/LAV) Infection Among Intravenous Drug Abusers’, *British Medical Journal*, 292 (1986), pp. 527-9.

⁹⁴ *Ibid.*

⁹⁵ Brett, ‘Did the Band Play On?’, p. 4.

⁹⁶ *Ibid.*

⁹⁷ *Ibid.*, p. 6.

⁹⁸ LHSA, EUL, GD24, C5, D3, (2.1.1), Lothian AIDS Advisory Group –Agenda and Minutes, Minutes of LAAG, 26 June 1985.

members of the LAAG.⁹⁹ By this time, MacDonald had replaced Dr John Reid. Prior to this time, MacDonald had been a Deputy CMO. At the meeting the SHHD were greeted with information on a broad canvas. They were told that the HTLV-III virus was not new but had been around for two years and that a number of intravenous drug misusers had presented to the City Hospital with conditions indicative of 'pre-AIDS'. There were also two babies who were HTLV-III antibody positive who were being kept in hospital because no-one wanted them. One consultant informed the meeting that patients were not being 'handled well psychologically'.¹⁰⁰ For example, drug misusers requiring surgical treatment were being sent immediately to the City Hospital because of staff fears about treating them. Finally, it was forecast that within two years Lothian would be overstretched and unable to cope with AIDS.

At the meeting it was noted that, although Robertson had been supplying free needles to some drug misusers at his practice in the West Granton area of Edinburgh, the practice of sharing continued.¹⁰¹ Robertson stressed the importance of a Primary Care service for drug misusers which would need to be more fully resourced than at present. The ensuing discussion recognized the need for a balance to be struck between the prevention of the spread of HTLV-III and a solution to the problem of drug addiction. The significance of intravenous drug abuse as a 'window' into the heterosexual spread of HTLV-III was highlighted. New evidence suggested that female to male heterosexual spread was occurring among prostitutes and their clients in Africa.¹⁰²

⁹⁹ NAS, HH61/1125, 'Note of Meeting held on Friday 13 December 1985 Between the CMO and Members of the Medical Profession in Edinburgh to Discuss Problems Arising from HTLV-III Infection and Intravenous Drug Abuse'.

¹⁰⁰ *Ibid.*

¹⁰¹ *Ibid.*

¹⁰² *Ibid.*

The CMO closed the meeting with no firm commitment from his Department. He said 'that while a problem had been identified in Lothian which was being tackled locally, the meeting had been extremely useful as a first step in assessing what might be done on a national scale'.¹⁰³

This chapter has shown that, by the end of 1985, concern about the increasing incidence of HTLV-III led to a number of measures, taken amid the uncertainty of disease and associated fear and panic over the potential for spread. Responses were complex however and took into account issues of medical confidentiality and protection from stigma. Actions were also informed by past experience of disease. For its part, the Scottish media simultaneously reinforced and allayed fears about the spread of the disease in the City.

During 1985 the SHHD followed suit with England and Wales regarding notification and testing, yet departed over the issue of disclosure in the context of educational guidelines. However, in the face of growing anxiety over the incidence of HTLV-III in Edinburgh, increasingly brought to their attention by the local policy community, the SHHD remained reluctant to become directly involved in issues deemed to be politically sensitive. As will be shown in Part Two, the policy response to AIDS between 1986 and 1987 became increasingly controversial, especially with respect to the prevention of HTLV-III amongst intravenous drug misusers.

¹⁰³ *Ibid.*

PART TWO – THE RESPONSE TO AIDS IN EDINBURGH – 1986 – 1987

Part Two will focus on the policy response to AIDS in Edinburgh between 1986 and early 1987, a period of intense activity. It will be shown that the response was increasingly dominated by perceptions of AIDS as a disease associated with drug misuse. By the end of 1986, concerns about AIDS led to greater involvement from the statutory sector and the Scottish Office. Chapter 5 concentrates on the period from early 1986, and the establishment of a Scottish Committee to investigate the problems of HIV and drug misuse and goes on to analyse differences in policy response between the UK government and the Scottish Office, with respect to health education and government guidelines. Finally, attention is paid to local screening measures, particularly those which focused on women with a history of drug misuse, who came to be seen as the new vectors of disease, and shows how these local measures came to inform national screening initiatives.

Chapter 6 deals with the end of 1986 and early 1987, following the publication of the Scottish Home and Health Department's (SHHD) report on HTLV-III and intravenous drug misuse, known as the McClelland report.¹ A focus is made upon some of the Report's findings and recommendations in order to highlight its influence in stimulating local action, particularly joint action between statutory and non-statutory agencies. Attention is also given to debates within the areas of education, needle exchange and substitute drug therapy, disclosing tensions between government departments and local agencies over how far strategies to protect public health should prevail over strategies to treat drug misusers.

¹ Scottish Home and Health Department, *HIV In Scotland – Report of the Scottish Committee on HIV Infection and Intravenous Drug Misuse* (Edinburgh, September 1986).

CHAPTER 5 – ‘THE AIDS CAPITAL OF EUROPE’ - 1986 - 1987

This chapter deals with the response to AIDS in the first half of 1986. Firstly, it shows how Edinburgh's HTLV-III problem provided the impetus for the establishment of a Scottish Home and Health Department (SHHD) committee to investigate the connections between HTLV-III and drug misuse. Secondly, by paying attention to the Scottish Office's input during this time, it will be shown that there continued to be an ongoing lack of directive in health education. It also demonstrates continuing differences between health departments, especially over the issue of disclosure, reflecting the influential role played by medical opinion in Scotland in defining policy. Finally, this chapter explores screening measures introduced in Edinburgh by Lothian Health Board (LHB), during the early part of 1986, in connection with AIDS and drug misuse. These reveal how the response to AIDS focused initially on female drug misusers and demonstrate that the relationship between disease and the control of infection was shaped by wider apprehensions about women and their role as mothers. Linked to this was the role of women and prostitution, which served to reinforce perceptions of women as vectors of disease and subsequently informed national decisions on screening.

Scottish Advisory Committee on HIV Infection and Intravenous Drug Misuse (SCHIIDM)

By early 1986, Edinburgh's HTLV-III problem had become an issue of national concern. Dr Ian MacDonald, the Chief Medical Officer (CMO) of the SHHD and Donald Acheson, the CMO at the Department of Health and Social Security (DHSS),

had been invited to attend a meeting of the All-Party Parliamentary Committee on Drugs Misuse. The Committee had been anxious about the spread of HTLV-III among intravenous drug users and the potential for spread into the heterosexual population. MacDonald gave an account of the problem in Edinburgh and announced that he had appointed a Scottish Committee to monitor the situation and provide advice over possible action. He stressed the need for a co-ordinated approach, with the involvement of national committees such as the Expert Advisory Group on AIDS (EAGA) and the Advisory Council on the Misuse of Drugs (ACMD). There followed a lengthy discussion about the supply of needles and syringes as a means of controlling the spread of AIDS. Parliamentary committee members were very much opposed to the idea on the grounds that the initiative might be construed by some as condoning drug misuse.²

The terms of reference for the new Scottish Advisory Committee on HIV Infection and Intravenous Drug Misuse (SCHIIDM) were:

To review the extent of infection by the HTLV-III virus in Scotland, particularly amongst intravenous drug misusers, and to consider what steps should be taken to contain the spread of infection and to allay public concern.³

In addition to SHHD representatives, almost half of the membership (six out of fourteen) consisted of Edinburgh-based doctors or scientists. Amongst them were Ray Brettle, Roy Robertson, George Bath and John Peutherer, all of whom had carried out studies revealing the extent of HTLV-III in the City. In addition, the

² NAS [National Archives of Scotland] HH61/1125, Minute, I. S. Macdonald to W. K. Fraser and P. Cox, 16 January 1986.

³ Scottish Home and Health Department, *HIV In Scotland – Report of the Scottish Committee on HIV Infection and Intravenous Drug Misuse* (SHHD, Edinburgh, September 1986), p. 1. By the time the Report was published HTLV-III had become known as Human Immunodeficiency Virus (HIV).

Committee was chaired by Brian McClelland, who had been heavily involved in local Edinburgh measures with respect to AIDS and blood donations. He was also a member of the EAGA and therefore provided links between national and local concerns. Other doctors were from Glasgow and Dundee and, latterly, Aberdeen. Only one member was from the voluntary drug sector and another was a high school rector.

The Supply of Needles and Syringes

At the first meeting of SCHIIDM in February 1986, MacDonald warned that there had been a great deal of media interest surrounding the issue of supplying needles and syringes. He stressed that an informed and balanced view was required in order to agree an interim report of recommendations, so that ministers had an early indication of the Committee's view.⁴ The SCHIIDM concluded that not enough was known about the behaviour of the disease in this drug-misusing group to enable them to be confident that the provision of needles and syringes would reduce the spread of infection. Nonetheless, they felt that, in light of evidence presented at the meeting, mostly from Edinburgh studies, it was likely that they would recommend as a first step that General Practitioners (GPs), who considered it necessary, should be encouraged to issue needles and syringes on a new-for-old exchange basis.⁵ This view was not surprising given the extent of the membership who favoured this approach. Robertson, Brette, Bath and Robert Covell (SHHD representative member) were sympathetic to harm minimisation methods as a means of infection

⁴ Lothian Health Services Archive [LHSA], Edinburgh University Library [EUL], GD24, C5, D3, (2.4.1), SCHIIDM Agenda and Minutes – February 1986 – ‘Scottish Committee on HTLV III Infection and Intravenous Drug Misuse – Minutes of First Meeting held on 27 February 1986’.

⁵ *Ibid.*

control, particularly the supply of needles and syringes. In addition, prior to the first meeting, McClelland and Covell had made a fact-finding tour of Amsterdam to gain information on the management of drug misuse there and gauge its relevance to the prevention of HTLV-III. They noted that revolutionary and radical steps, including the distribution of injection equipment had been taken in Holland, which did not 'appear to have made the drug misusing situation any worse and may have improved it'.⁶ Clearly, there were some committee members, especially Edinburgh-based ones, who were already convinced that this was the best approach.

In the meantime, in Edinburgh, the press was used by key Edinburgh public health officials, including some SCHIIM committee members, to express the views of those in favour of needle and syringe exchange. For example, *The Scotsman* informed its readers about a group of local doctors and academics who claimed that at least 100 drug users could die of AIDS within the next two years. The article stressed that numbers could be higher unless doctors were allowed to supply needles and syringes to drug users as a means of stopping the spread of the AIDS virus in the city.⁷ Similarly, the Head of Environmental Health for Edinburgh District Council, Richard Carson, stated that known drug users in certain areas of Edinburgh aged between 16-25 years, should be issued with sterile needles and syringes by GPs to restrict the spread of Hepatitis B and AIDS.⁸ He argued that, if City officials had taken advice in the early 1980s and supplied sterile injecting equipment to curb the local outbreak of Hepatitis B, this would also have been effective in curbing the

⁶ NAS, HH61/1125, 'Preliminary Report – Visit to Amsterdam – 20 February 1986'.

⁷ G. Dean, '100 could die of AIDS in Capital', *The Scotsman*, 22 February 1986, p. 1.

⁸ J. Johnston, 'Issue of Sterile Needles to Drug Users Urged to Combat AIDS', *The Scotsman*, 11 March 1986, p. 6.

spread of HTLV-III.⁹ A spokesperson for the Lothian Health Board (LHB) added that the Board was examining the possibility of issuing needles and syringes.¹⁰

Other articles in the media tended to reinforce the AIDS related panic in Edinburgh. One Edinburgh consultant claimed that ‘addicts often valued the effect of heroin more than anything else, including life itself ... and there is one chap ... who is just carrying on as normal’.¹¹ In a similar panic-inducing vein, the Edinburgh *Evening News* created a story about the legacy of an ‘unknown addict’ who, by sharing a needle with one or more local addicts, caused Edinburgh to become the second-highest centre of AIDS-infected drug misusers in the world.¹² In the UK press, Edinburgh was becoming known as the ‘AIDS Capital of Europe’.¹³

Although some in the SHHD, such as Covell, saw the benefits of supplying free needles and syringes to drug misusers, the issue was complicated and controversial due to political, financial and legal considerations. John MacKay, Scottish Minister for Health and Social Affairs, was interviewed on television in early February 1986 and stated his total opposition to issuing free syringes and needles under any circumstances.¹⁴ Among other reservations, officials argued that free provision to drug misuse would be perceived as unfair to sufferers from diabetes who had to pay for needles and syringes out of their own pockets.¹⁵ Furthermore, although GPs could

⁹ LHSA, EUL, GD24, C5, D2, (2.2.0), Regional AIDS Group General Part 1- Document, R. A. Carson, ‘AIDS as a Communicable Disease – A Discussion Document and City Strategy’, 1987.

¹⁰ J. Johnston, ‘Issue of Sterile Needles to Drug Users Urged to Combat AIDS’, *The Scotsman*, 11 March 1986, p. 6.

¹¹ S. Bain, ‘Cash Spent on Addicts ‘Wasted’’, *The Scotsman*, 11 January 1986, p. 1.

¹² S. McNamara, ‘The Sinister Legacy of an Unknown Addict’, *Edinburgh Evening News*, 10 January, 1986.

¹³ C. Dawson, ‘Babies of the ‘AIDS Capital’’, *The Sunday Telegraph*, 13 April 1986.

¹⁴ NAS, HH61/1247, Letter, J. R. Robertson to J. Douglas-Hamilton, 6 February 1986. See also, Letter E. Shaw, DHSS to A. Macpherson, SHHD, 11 February 1986.

¹⁵ *Ibid*, Letter, A. Macpherson to E. Shaw, 17 March 1986.

prescribe syringes and needles under the terms of their service with the NHS, it was felt that many would be reluctant to do so for fear that it could be construed as ‘aiding and abetting’ an illegal act.¹⁶ A recent conviction had been obtained for the sale of items for use in glue sniffing practices, for example.¹⁷ In this context, the sale of items intended for drug misuse in Scotland was still governed by Common Law, unlike in England and Wales where this was regulated by the Intoxicating Substances (Supply) Act 1985.

These implications caused tensions between the SHHD and the DHSS, who wanted to press ahead with the introduction of needles and syringes in England and Wales.¹⁸ Unlike the SHHD, the DHSS did not see the measure as creating any major political or financial problems. Only a small minority of drug misusers in England injected their drugs. The DHSS subsequently drafted a position paper for the ACMD who were due to meet in May 1986.¹⁹ Commenting on their draft, the SHHD felt that little consideration had been given to the full implications of needle and syringe supply. In a stern letter to the DHSS, Angus Macpherson, Assistant Secretary of the SHHD, with responsibility for health education and prevention, wrote saying that, if England adopted such a policy, it would put the SHHD in a very difficult position.²⁰ Subsequently, the position paper was amended to take account of the SHHD comments and was presented to the ACMD accordingly, ahead of the SCHIDM’s report.²¹

¹⁶ *Ibid.* See also, Minute, D. Howieson, to H. McBain, 13 January 1986.

¹⁷ *Ibid.*

¹⁸ *Ibid.*, Letter E. Shaw to A. Macpherson, 11 February 1986.

¹⁹ *Ibid.*, ‘Position Paper on AIDS and Drug Misusers – Syringes and Needles’, March 1986.

²⁰ *Ibid.*, Letter, A. Macpherson to E. Shaw, 17 March 1986.

²¹ NAS, SOE14/129, Letter R. G. W. Cook, Home Office to Welsh Office, 30 April 1986.

Shortly after its meeting, the ACMD recommended that injecting equipment should not be made more readily available because this would encourage greater drug misuse.²² This view was welcomed by the SHHD, because it gave them more time, to consider their options before the McClelland committee finalised its report. However, by this time other national bodies such as the EAGA were beginning to express their views in favour of needle and syringe supply, despite the potential risk of greater misuse of drugs.²³

While these opinions were being voiced up and down the country, the SCHIDM had held its third meeting in June 1986 and had agreed to recommend that:

subject to legal clearance practitioners should be informed that it may be an appropriate part of the management of individual patients, in the interest of limiting the spread of infection, to issue needles and syringes and that this should be done on a one-to-one exchange basis for a needle and syringe.²⁴

Like the EAGA, the public health emphasis from the SCHIDM was clear. The Scottish Committee included specialists from Edinburgh in both public health and infectious diseases, all of whom were focused and concerned to ensure that appropriate measures would be in place to contain the spread of HTLV-III/AIDS over and above the need to contain the spread of drug misuse.

As will be discussed in the next chapter there remained strong resistance to the idea of free supply of needles and syringes long after the publication of the McClelland

²² *Ibid.*, HH61/1126, 'AIDS – Second Revised Draft', August 1986.

²³ *Ibid.*

²⁴ LHSa, EUL, GD24, C5, D3, (2.4.1), SCHIDM Agenda and Minutes – February 1986 – 'Scottish Committee on HTLV III Infection and Intravenous Drug Misuse – Minutes of Third Meeting held on 5 June 1986'.

Report. Such views would ensure that the final approval of the measure would be a slow process in Scotland.

Public Education and National Guidelines

Mass Media Campaign - 1986

Although local health education initiatives were an important part of the response to AIDS in Edinburgh during 1986, they tended to be targeted at high-risk groups or in the form of local guidelines and seminars for staff members of statutory agencies. The Scottish AIDS Monitor (SAM) continued to provide information and advice to the gay and drug-misusing communities, as did a number of voluntary drug projects. Indeed, SAM's contributions to the reduction in sexually transmitted diseases amongst the gay community in Edinburgh had been commended by Sandy McMillan, Consultant in Genito-Urinary Medicine (GUM).²⁵ Statutory agencies such as the Lothian Regional Council (LRC), the Edinburgh District Council (EDC) and the LHB were also instrumental in providing information and guidelines on AIDS to their staff members. One exception, where the target was aimed at the general public, was an advertising campaign initiated by SAM in association with Scottish Television. This featured the pop band, The Communards, who had a recent number one hit with 'Don't Leave Me this Way'. The band advised young people about the risks of AIDS on television.²⁶

²⁵ W. Jack, 'Waiting for the AIDS Onslaught', *The Scotsman*, 8 December 1986, p. 6. See also, A. McMillan, 'Human Immunodeficiency Virus in Homosexual Men', *Scottish Medical Journal*, 32, 1987, pp. 107-9.

²⁶ 'Communards' in AIDS Ad.!', *Gay Scotland*, 15 (December 1986), p. 3.

However, it was at the national level that educational initiatives aimed at the general public, in response to AIDS, took place. At the end of 1985, Norman Fowler, the Secretary of State for Social Services, allocated £2.5 million for a public information campaign.²⁷ This took the form of a mass media campaign, launched in March 1986, with advertisements about AIDS placed in newspapers. The Scottish Office was apprehensive about placing advertisements in the Scottish Press. Prior to the launch, John MacKay announced on television and in the Scottish press that these adverts would shock some readers.²⁸ The first appeared in March 1986. Commenting on one of the adverts, one reader said he was ‘quite appalled thereby; it was uselessly crude, it was inaccurate, and it was misleading [and] looked like the work of the night-shift boilerman, rather than the approval of a committee or two’.²⁹ The SAM was also among the critics. They felt that the adverts were ‘bland and that the diagram of an AIDS nucleoid was meaningless and might as well have been a picture of Halley’s Comet’.³⁰ Similar feedback about obscurity and the lack of impact were also shared outside of Scotland.³¹

It is unclear whether these criticisms played a part in SHHD’s decision not to relaunch the advertisements in July and October, as happened elsewhere in the UK. The reasons the SHHD gave were that a campaign in July would be ineffective because of the Scottish holiday period.³² In October, they felt the expenditure was not justified due to ‘other pressing claims’.³³ Instead they were able to benefit from the UK

²⁷ NAS, HH6/1309, DHSS Press Release, ‘Extra £6.3 Million to Combat AIDS’, 2 December 1985.

²⁸ See, ‘AIDS Adverts Likely to Shock’, *The Scotsman*, 14 March 1986, p. 1.

²⁹ NAS, HH61/1295/1, Letter to John MacKay, 17 March 1986 [name of individual removed under Freedom of Information (Scotland) Act, 2002].

³⁰ See, B. Pendreigh, ‘Poor Start to AIDS Campaign’, *The Scotsman*, 17 March 1986, p. 7.

³¹ V. Berridge, *AIDS in the UK: The Making of Policy, 1981-1994* (Oxford, Oxford University Press, 1996), p. 89.

³² NAS, HH61/1278, ‘Annex B – AIDS in Scotland’, SHHD, November 1986.

³³ *Ibid.*

government publicity, which spilled over into Scotland from the national newspapers and thereby avoided any direct repercussions from the public over the explicit nature of the advertisements.³⁴ Thus, at a time when Edinburgh's incidence of HTLV-III was amongst the highest in the UK, little effort on the part of the Scottish Office was made to warn the general public of the dangers of infection. As with the issue of needles and syringes, they were reluctant to take a firm stance in areas deemed to be controversial. This stance also confirmed and compounded the continued lack of agreement over a co-ordinated approach by government departments north and south of the Border in their response to AIDS.

Government Guidelines

The lack of unity between government departments in responding to AIDS is also reflected in the issue of guidelines for schools and prisons. As was noted in Chapter 4, interim guidelines for educational establishments had resulted in different measures in Scotland and elsewhere in the UK at the end of 1985, especially in connection with haemophiliac children over the issue of disclosure. The need for disclosure to individuals beyond those in the medical profession had remained a source of tension within the Scottish Office in the context of guidelines for educational establishments and for prison and social work departments. The SHHD clearly advocated non-disclosure, believing that given the then state of knowledge about AIDS, information about persons who may be HTLV-III positive should be confined to those responsible for their medical care.³⁵ The Scottish Education Department (SED) had favoured a degree of disclosure but continued to be concerned that advice to schools to treat

³⁴ The Scottish Health Minister, Mr John MacKay, warned that the AIDS advertisements would shock some readers. See, 'AIDS Adverts Likely to Shock', *The Scotsman*, 14 March 1986, p. 1.

³⁵ NAS, ED39/475, Minute, A. M. MacPherson to J. MacKay, 10 January 1986.

every spillage of blood or vomit as potentially infectious, as outlined in their interim guidelines, would cause undesirable panic or simply be ignored.³⁶ At the political level, MacKay was in favour of wider disclosure because he felt that AIDS was no ordinary disease and every step should be taken to guard against its spread to 'innocent people'.³⁷ However, it would appear that the SHHD persuaded MacKay to reconsider his view because, when the issue was discussed at a meeting of the Interdepartmental Group on AIDS held in January 1986, a representative from the Scottish Office said that Scotland would maintain the general principle of confidentiality and non-disclosure.³⁸

Some government departments south of the Border appeared to have shared the views of the SHHD, and in summing up the meeting the Chairman said there was a preference for adopting a rule of confidentiality with disclosure only in exceptional circumstances.³⁹ By March 1986, the Department of Education and Science (DES) guidelines, *Children at School and Problems related to AIDS*, was issued with the original draft reworded to advise against disclosure.⁴⁰ In Scotland, the SED distributed copies of *AIDS – Guidance for Educational Establishments in Scotland* in January 1987, which was an updated version of its interim measures introduced at the end of 1985. These also emphasised the importance of non-disclosure.⁴¹

³⁶ *Ibid*, Minute, W. Moyes to D. A. Leitch, 22 January 1986.

³⁷ *Ibid*, J. MacKay to A. M. MacPherson, 13 January 1986.

³⁸ NAS, HH61/1310, Minutes of the First Meeting of the Inter-Departmental Group on Aids, 21 January 1986.

³⁹ *Ibid*. See also, Berridge, *AIDS in the UK*, pp. 100-1.

⁴⁰ Berridge, *AIDS in the UK*, pp. 100-1.

⁴¹ Department of Education and Science, *Children at Schools and Problems Related to AIDS* (DES/Welsh Office, 1986) and Scottish Education Department, *AIDS: Guidance for Educational Establishments in Scotland* (SED, 1987). See also, NAS HH61/1248 for copies.

However, differences over the issue of disclosure remained in other guidelines, such as those for the prison service. For example, Scottish Prison Service guidelines had adopted a policy of non-disclosure and non-segregation and made it clear that there were no medical reasons for segregating inmates who were known to be infected, or for limiting the normal range of work or recreational activities in which they might engage.⁴² This enlightened approach was in direct contrast to those produced by the Home Office for England and Wales in late 1985 where a prisoner who was known to be HTLV-III positive was segregated under Viral Infectivity Regulations (VIR) and prison staff informed of his status. Some claim these differences were due to union pressures south of the Border.⁴³ While this may be true, the medical influence in the SHHD in defining Scottish AIDS policy is clear with regard to prison guidelines.

The above accounts of policy decisions at the national level shows that there were striking differences between government departments, emphasising a lack of consensus in all of the areas of policy discussed above. However, as will be discussed below, there were some areas of policy discussion that reflected greater consensus of opinion, especially the need to screen pregnant women for HTLV-III.

Women Become the Focus of Attention in Edinburgh

While the above issues were being debated at the national level, local policy development was being pursued in connection with AIDS and drug misuse. Amongst the first to respond was the LHB who began to focus upon women with HTLV-III. The research findings from all three local studies carried out during the second half of

⁴² NAS, SOE14/129, Briefing Document, April 1987.

⁴³ *Ibid*, HH57/1733, Minute, C.M. Reeves to SHHD, 13 October 1988.

1985 showed that a high percentage of female drug misusers in Edinburgh were HTLV-III positive.⁴⁴ Some of these women were expectant mothers. The results highlighted the potential for heterosexual and mother-to-child transmission of the virus on a wider scale than previously imagined. The subsequent response sheds light on the stark nature of the AIDS policy response towards young women, and young pregnant women in particular.

Women as Mothers

By the end of the 1985, the LHB had begun to draw up proposals for a separate AIDS Maternity Unit at the Elsie Inglis Hospital. They stressed that such a facility was based on the need to provide appropriate medical treatment for AIDS carriers, rather than concerns about the spread of infection.⁴⁵ However, the LHB were under pressure at the same time to respond to concerns over protection of staff from infection at the Department of Obstetrics and Gynaecology at the Simpson Memorial Maternity Pavilion (SMMP).⁴⁶ Staff there believed they were at greater risk of infection, especially during delivery procedures. The issue was discussed at the Lothian Area Medical Committee (LAMC), where members of the Division of Paediatrics objected to the proposals of a separate unit, since extra resources would be spent on 'heroin

⁴⁴ J. F. Peutherer, E. Edmond, P. Simmonds, J. D. Dickson and G. E. Bath, 'HTLV-III Antibody in Edinburgh Drug Addicts', *The Lancet*, 326 (1985), pp. 1129-30; J. R. Robertson, A. B. V. Bucknall, P. D. Welsby, J. J. K. Roberts, J. M. Inglis, J. F. Peutherer and R. P. Brett, 'Epidemic of AIDS Related Virus (HTLV-III/LAV) Infection Among Intravenous Drug Abusers', *British Medical Journal*, 292 (1986), pp. 527-9; R. P. Brett, J. Davidson, S. J. Davidson, J. M. N. Gray, J. M. Inglis, J. S. Conn, G. E. Bath, J. Gillon and D. B. L. McClelland, 'HTLV-III Antibodies in an Edinburgh Clinic', *The Lancet*, 327 (1986), p. 1099.

⁴⁵ B. Christie, 'Mothers with AIDS May be Isolated', *The Scotsman*, 23 November 1985, p. 1.

⁴⁶ LHSA, EUL, GD24, C5, D3, (2.1.1), Lothian AIDS Advisory Group – Agenda and Minutes, Minutes, 13 November 1985.

addicts' who seldom appeared for regular appointments.⁴⁷ They maintained that the adoption of extra precautions at SMMP would be adequate enough and resources could be utilised elsewhere. It would appear that a compromise was made, since an agreement was reached between the Obstetricians and the LHB to create isolation facilities within the SMMP.⁴⁸ This was to be on the ground floor and to consist of three rooms, each containing a shower and wash hand basin. Furthermore, it was proposed that in the labour ward, one room should be identified exclusively for high-risk infection patients.⁴⁹ Thus, young pregnant women, who were HTLV-III positive, came to be isolated from other women in order to receive the appropriate medical care for themselves and their babies. Being separated from other mothers at a time when they had to cope with the implications of HTLV-III for themselves and/or their babies would have been an additional burden.

While policies focussing on women purported to be in interests of the welfare of child and mother, they were often conflated, as indicated above, by other factors, such as staff fears of infection, especially during delivery. Clearly, the issue of protection from stigma complicated considerations in the context of measuring infection risk. As with previous responses to AIDS in Edinburgh, as outlined in Chapter 4, the balance between concerns about staff safety on the one hand and protection from stigma for patients on the other continued, in some areas, to weigh on the side of staff. The difference on this occasion was that drug misusing women had become the new vectors of disease. Furthermore, while Scottish Office policies were being

⁴⁷ LHSA, EUL, LHB/37/2/512, Lothian Area Medical Committee (LAMC) Minutes 1973-1986, Minutes, 27 November 1985. The LAMC was made up of medical representatives in each of the health care divisions from all the hospitals managed by Lothian Health Board.

⁴⁸ *Ibid*, GD24, C5, D3, (2.1.1), Lothian AIDS Advisory Group – Agendas and Minutes, Minutes, 5 March 1986.

⁴⁹ *Ibid*, Document 'AIDS Virus Infection and Obstetric Care' (May 1986).

implemented to protect individuals from stigma within educational establishments, prisons and social work departments, there continued to be potential stigmatisation within medical establishments, where risks to staff were seen to be greater.

Advice for Antenatal Women with HTLV-III

By the middle of 1986, a programme was introduced by obstetricians which offered both a counselling and testing service (with consent) for women found to be at high risk from infection.⁵⁰ All women who attended an antenatal booking visit were asked a routine question about drug misuse, whether by herself or her partner. Screening for those found to be in a high risk category was considered necessary in order to offer the best clinical advice to patients found to be HTLV-III positive. At this time, it was believed that pregnancy could accelerate the speed with which seropositive HTLV-III women developed AIDS and that there was a very high risk of infecting their child with the virus.⁵¹

The obstetricians received back-up specialist advice from Brettle, who had set up a special counselling clinic, where he advised any woman found to be seropositive to either avoid pregnancy, or if they were pregnant, to seek a termination. The advice was severe, but as far as Brettle was concerned these women could be dead within three years and their babies could be dead within one year.⁵² Brettle's advice was based on evidence from one study that had been carried out in Florida on 16 women,

⁵⁰ *Ibid.*

⁵¹ House of Commons, Social Services Committee's Third Report, *Problems Associated with AIDS*, Vol. II, *Minutes of Evidence*, 4 February – 25 March, 1987 (London, 1987), p. 194.

⁵² *Ibid.*

where the outlook was pessimistic.⁵³ Although Edinburgh was probably amongst one of the first to offer this advice, the same recommendations regarding termination were advocated in guidelines produced by the Royal College of Obstetricians and Gynaecologists from 1986.⁵⁴

Brettelle stipulated that the decision to have a test and/or subsequently an abortion was ultimately left up to the individual. However, it must have proved difficult for many women to ignore the advice given. Some clinicians argued that a reduction in the number of babies born with the virus during early 1987 was attributed to advice about preventing pregnancy and termination.⁵⁵ For those women at risk who decided to proceed with pregnancy, permission was sought to include them in a perinatal transmission study.⁵⁶ By April 1987, Dr Jacquie Mok, Consultant Paediatrician, based at the City Hospital, had followed up 29 mothers, all of whom she reported to be in good health despite having recently given birth. Only two of the HTLV-III infected children had developed signs of the illness. However, Mok found that the AIDS virus had been difficult to identify in such children since they all had AIDS antibodies in their blood through their mother, but were expected to expel these by the age of approximately 9 months.⁵⁷

From the LHB's point of view, there were financial reasons why the advice given to HTLV-III positive women was seen as appropriate. The LHB had become worried

⁵³ *Ibid.*

⁵⁴ Berridge, *AIDS in the UK*, p. 97.

⁵⁵ J. O'Sullivan, 'Fall in Births to AIDS-Infected Mothers', *The Scotsman*, 7 April 1987, p. 3. The use of the term HTLV-III was increasingly replaced or used interchangeably by the term Human Immunodeficiency Virus (HIV) during 1986.

⁵⁶ For a history of the paediatric screening and counselling service see, LHSA, EUL, GD24, B3, Lothian Health Board, *AIDS in Lothian: Facing the Facts 1990 – A Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending 31 March 1990), Appendix 2, p. 7.

⁵⁷ J. O'Sullivan, 'Fall in Births to AIDS-Infected Mothers', *The Scotsman*, 7 April 1987, p. 3.

about the burden of care that might be placed on their paediatric facilities should increasing numbers of sick children be born to HTLV-III positive mothers.⁵⁸ During 1986, over 20 HTLV-III positive babies had been born and it was unclear at the time how many were likely to develop AIDS. This occurred at a challenging time for the LHB, who had a financial deficit, and were adapting to the changes following the recommendations in the Griffiths Report (1983). This brought a new General Manager to the LHB, Mr Winston Tayler, in early 1986, who was faced with the task of retrenchment and redevelopment of services.⁵⁹

The Social Work Department (SWD) at the LRC were equally concerned about having to find resources to cope with the challenge of care provision for babies born to HTLV-III positive drug misusers, who were too sick to look after their children.⁶⁰ The concerns of the SWD were further accentuated by financial cutbacks imposed by a conservative administration on the LRC.⁶¹

Overall, such policy measures served to reinforce perceptions of women as vectors of disease, through mother-to-child transmission. However, female drug misusers were also singled out as the vectors of heterosexual transmission of AIDS, as many were

⁵⁸ House of Commons, Social Services Committee's Third Report, *Problems Associated with AIDS, Vol. II, Minutes of Evidence, 4 February – 25 March 1987* (London, 1987), p. 180.

⁵⁹ See, Department of Health and Social Security, *NHS Management Enquiry Report*, (Griffiths Report), (London, DHSS, 1983). See also, C. Bennett and A. Pettigrew, 'Waiting for AIDS: The Response to HIV Infection in Lothian – Summary Report', (Centre for Corporate Strategy and Change, University of Warwick, September 1989), p. 5.

⁶⁰ NAS, ED39/741, Minute of Meeting of Directors of Social Work on AIDS, 7 November 1986. See also, 'Preparing for a Major Change – Lothian Aims to Keep AIDS Babies out of Institutions', *Community Care*, (10 April 1986), pp. 4-5.

⁶¹ C. Bennett and A. Pettigrew, *Waiting for AIDS*, p. 3. The LRC was formed in 1975 and comprised the Districts of East Lothian, Midlothian, West Lothian and Edinburgh. It was responsible for education, social work, water, sewerage and transport. It also had joint responsibility with the Borders Regional Council for the Lothian and Borders Police Force and Fire Brigade. The LRC had suffered increasing financial cutbacks since the Conservatives had come to power in 1979.

thought to support their habit by prostitution in a chaotic lifestyle.⁶² Assumptions were made that drug addiction took priority over other considerations such as safe sex in these women. These perceptions were reinforced by the media, whose portrayal of the disease was firmly linked to the role of prostitution, and the threat posed to the wider public by female drug addicts who earned money through the sex trade. They were seen as the 'bridging group' between drug misusers and unsuspecting members of the public.⁶³ It was feared that men that visited prostitutes were putting themselves and their families at risk. Some of the press reported that 'street girls' were continuing to engage in high-risk behaviour and touting for business in the Leith area of Edinburgh, 'where they charged £10 a time for sex, enough to buy one fix of heroin'.⁶⁴ Another press report told the story of Anne, 21 years old, a prostitute who was dying of AIDS.⁶⁵ Anne apparently wanted her photo exposed in the press in order to be recognised by her former clients, who could seek help. She claimed that she had 'been with hundreds of men since getting AIDS through the use of a dirty heroin needle'.⁶⁶ She also stated that she was by no means the only prostitute who knew they had AIDS but were continuing to work to feed their habit.

Screening Measures for Women

By early 1987, the benefits of screening measures for all women began to emerge. Brettle was interested in the role of heterosexual transmission, from male to female,

⁶² House of Commons, Social Services Committee's Third Report, *Problems Associated with AIDS*, vol. II, *Minutes of Evidence*, 4 February – 25 March 1987 (London, 1987), pp. 175-6.

⁶³ Quoted in R. McKie, *Panic – The Story of AIDS* (Wellingborough, New York, Thorsons Publishing Group, 1986), p. 44.

⁶⁴ C. Dawson, 'Babies of the 'AIDS Capital'', 13 April 1986. See also, M. Harker, 'Street Girls Still Taking AIDS Risk', *Edinburgh Evening News*, 11 February 1987.

⁶⁵ G. Goodwin, 'Tell My Story – AIDS Anguish of Dying Vice Girl', *Scottish Sunday Mail*, 14 December 1986.

⁶⁶ *Ibid.*

and female to male. He believed that Edinburgh was an important research environment for the UK because it could have had the 'answer to the rate of transmission'.⁶⁷ Brettle suggested to the House of Commons Social Services Committee, who were investigating the problems associated with AIDS during 1986 and 1987, that anonymous screening of all pregnant women in Edinburgh (which would incur no counselling costs) should be undertaken as an appropriate step before making decisions on screening women with their consent.⁶⁸ Bath, a Community Medicine Specialist, also saw some advantages of a screening programme for all pregnant women because it was one of the most convenient ways of gaining epidemiological information about the sexually-active population. By this logic, as all pregnant women had blood taken for a number of routine tests during their antenatal booking visit, additional samples for HIV screening would not be needed and therefore the process of screening would be easy and cheap.⁶⁹ This rendered women as an easy target for surveillance purposes, or in Lorraine Sherr's words 'sitting ducks'.⁷⁰ This also corroborates the findings of Davidson in Edinburgh, whereby routine antenatal VD testing had been encouraged by epidemiologists from as far back as the 1950s as a means of targeting groups of female vectors in the interests of public health.⁷¹

However, it was not only medical personnel who favoured wider screening measures for women. A local survey conducted in early 1987, indicated that some women in

⁶⁷ House of Commons, Social Services Committee's Third Report, *Problems Associated with AIDS, Vol. II, Minutes of Evidence, 4 February – 25 March 1987* (London, 1987), p. 194.

⁶⁸ *Ibid*, p. 198.

⁶⁹ LHSA, EUL, GD24, B3, Lothian Health Board, *AIDS in Lothian: Everyone's Concern 1988 – A Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending 31 March 1988), p. 40.

⁷⁰ L. Sherr, 'HIV Testing in Pregnancy', in C. Squire (ed), *AIDS and Women: Psychological Perspectives* (London, Sage, 1993), pp. 42-68.

⁷¹ R. Davidson, *Dangerous Liaisons: A Social History of Venereal Disease in Twentieth-Century Scotland* (Amsterdam, Rodopi, 2000), p. 274.

Edinburgh favoured screening for HIV during pregnancy.⁷² A total of 153 pregnant women who attended the Western General Hospital Maternity Unit in Edinburgh were asked if they would be willing to undergo screening and 90% said they would. Of these, 60% said they would seek a termination.⁷³ The extent to which this was representative of the views of all pregnant women in Edinburgh at the time is unclear. The Maternity Unit, where the study was conducted, was located in a part of Edinburgh attracting pregnant women from those parts of the city with the highest incidence of drug misuse, such as Pilton and Muirhouse. It could also be argued that media attention on AIDS and women in Edinburgh fuelled a certain degree of anxiety and fear amongst some women that led those from low risk groups to believe they were actually at risk.⁷⁴

The costs and benefits of screening all women in Scotland had also become a topic for discussion by MacDonald at the SHHD.⁷⁵ At the annual meeting of Obstetricians and Gynaecologists in Scotland, MacDonald, himself a trained obstetrician, was asked to comment on antenatal screening and 'expressed the view that the case for screening might well exist in Scotland, particularly in Edinburgh and Dundee, before it would be thought appropriate throughout other parts of the UK'.⁷⁶ He felt that there were clinical arguments (with respect to the management of patients) and possible epidemiological arguments allowing for assessment of the spread of HIV into the sexually active non-risk group via drug misusers.⁷⁷ The topic was subsequently put

⁷² 'Pre-Natal AIDS Test Gets Backing', *The Scotsman*, 1 April 1987, p. 5. This survey was widely publicised. See also, 'Pregnant Women Want AIDS Test', *The Guardian*, 27 March 1987 and 'AIDS: Test us Say Mums', *Edinburgh Evening News*, 27 March 1987.

⁷³ *Ibid.*

⁷⁴ See for example, 'High Female Total in AIDS Figures', *The Scotsman*, 11 April 1987, p.1.

⁷⁵ NAS, ED48/2203, 'Compulsory Screening and Voluntary Testing – A Supplementary Brief', 19 November 1986.

⁷⁶ NAS, HH61/1279, Minute, I. S. Macdonald to R. G. Covell, 1 December 1986.

⁷⁷ *Ibid.*

on the agenda of the newly-appointed Tayler Committee. This was a Scottish committee set up at the end of 1986 by Lord Glenarthur, the new Minister of State at the Scottish Office with responsibility for Health and Social Work. The Committee was chaired by Mr Winston Tayler, the recently appointed General Manager of the LHB, to advise on the 'most appropriate and cost-effective method of organising services for patients infected with the AIDS'.⁷⁸ Their Report, published in May 1987, recommended women who were HTLV-III positive should be advised on childbearing, termination and the risks of accelerating the development of AIDS during pregnancy. The Report also stated that:

Research should be undertaken as an urgent matter to establish if a more general application of screening, perhaps to the entire ante-natal population, is justified in terms of cost and benefit.⁷⁹

As will be shown in Chapter 7, which discusses the Tayler Report in greater detail, by the summer of 1987 the Scottish Office had agreed, for research purposes, to introduce wider antenatal screening measures in Edinburgh and Dundee.

Appearing simultaneously with the Tayler Report was that of the House of Commons Social Services Committee Report, which also made recommendations for specific screening measures for women. The Report recommended that testing, with informed consent, should be available to all pregnant women, with pre-test counselling, provided by trained medical and nursing staff.⁸⁰ The Committee's recommendations met with fierce opposition from Roman Catholic Church Leaders, including the head of the Roman Catholic Church in Scotland, who argued that this sort of policy would

⁷⁸ Scottish Home and Health Department, *Report of the National Working Party on Health Service Implications of HIV Infection* (Edinburgh, May 1987), p. 1.

⁷⁹ *Ibid.*, p. 5.

⁸⁰ House of Commons, Social Services Committee's Third Report, *Problems Associated with AIDS, Vol. I* (London, 1987), p. xiii.

put women found to be HIV positive under extreme pressure to have abortions or even to stop bearing children.⁸¹

General Screening Measures Rejected

The House of Commons Social Services Committee also discussed wider screening measures, both compulsory and anonymous screening, but argued against these on several grounds. Amongst the main reasons against the introduction of widescale screening were concerns about the infringement of civil liberties.⁸² Such concerns do not appear to have entered into debates on screening measures for women, thus demonstrating the gendered nature of policy. These gender differences in response to AIDS also resonate with the work of other historians who have used the social response to STDs to shed light on the discriminatory nature of sexual health policies towards women. Such policies are seen to reinforce gender divisions in wider society and reflect fears about broader issues such as urbanisation and the displacement of female labour.⁸³ In Edinburgh, policy measures for screening pregnant women at high risk of AIDS have also been shown to reflect wider concerns about women and their role as mothers. These also confirm the findings of other studies on the control of STDs whereby during periods of crisis, such as war, the gender discrimination informing sexual health policy is more apparent.⁸⁴ The panic surrounding AIDS in

⁸¹ J. O'Sullivan, 'AIDS Plan Attacked by RC Leaders', *The Scotsman*, 3 April 1987, p. 3.

⁸² House of Commons, Social Services Committee's Third Report, *Problems Associated with AIDS*, Vol. I (London, 1987), p. x-xi.

⁸³ See, for example, J. Walkowitz, *Prostitution and Victorian Society: Women, Class and the State* (Cambridge, CUP, 1980); R. Davidson, 'Venereal Disease, Public Health and Social Control: The Scottish Experience in Comparative Perspective', *Dynamis Acta Hist. Med. Sci. Hist. Illus.*, 17 (1997), pp. 343-9.

⁸⁴ L. Bland, 'In the Name of Protection: The Policing of Women in the First World War', in J. Brophy and C. Smart (eds), *Women-in-Law: Explorations in Law, Family and Sexuality* (London, Routledge and Kegan Paul, 1985), pp. 23-49.

Edinburgh, sparked initially by staff fears, led to women becoming the focus of concern and served to reinforce perceptions of them as vectors of disease.

The above account of the response to AIDS in Edinburgh during the early part of 1986 has shown that national debates over needle exchange and screening measures for women were heavily influenced by local doctors. However, the Scottish Office continued to differ from the UK with respect to its commitment to AIDS and drug misuse, and mass media education measures, especially those seen to be controversial. The Scottish Office also differed over the issue of disclosure of medical information, leading to different sets of guidelines educational establishments, prisons and social work.

The Scottish press, both tabloid and broadsheet, continued simultaneously to reinforce and allay fears about AIDS and drug misuse, with particular emphasis on women as the vectors of disease. As Chapter 6 will show, as we proceed into the period following the publication of the SCHIDM's Report, differences in policy-making at the national level continued to grow and played an important role in shaping the policy response at the local level.

CHAPTER 6 – THE RESPONSE TO AIDS IN EDINBURGH AFTER THE MCCLELLAND REPORT – 1986-1987

This chapter focuses on the response to AIDS in Edinburgh after the publication of the McClelland Report in September 1986.¹ The reaction to the Report is examined, particularly in the context of the need for a joint effort between statutory and non-statutory agencies to form a co-ordinated strategy, the introduction of health education measures, needle exchange schemes and substitute methadone therapy. It shows that the response to some of these measures gave rise to anxieties which resulted in further differences in policy responses between Edinburgh and the UK.

By the summer of 1986, the Lothian Health Board (LHB) had responded to AIDS in several ways. A Lothian AIDS Advisory Group (LAAG) had been created and guidelines on the care and treatment of AIDS and HTLV-III sufferers had been devised. Screening services, such as those for antenatal women at risk of AIDS and the ‘open access’ clinic at the City Hospital had also been established. The new General Manager, Winston Tayler, who took up his post at the beginning of 1986, claimed that AIDS ‘became a bigger issue as time went on’.² A number of individuals became increasingly concerned about the potential burden on hospital services. Amongst them was Ray Brettle and his colleagues at the Infectious Diseases Unit (IDU). They began to view the matter of AIDS with some urgency, especially the need for beds to accommodate sufferers. By September 1986, they had compiled

¹ This was the report published by the Scottish Advisory Committee on HIV Infection and Intravenous Drug Misuse, which became known as the McClelland Report. See, Scottish Home and Health Department, *HIV In Scotland – Report of the Scottish Committee on HIV Infection and Intravenous Drug Misuse* (Edinburgh, September 1986).

² Lothian Health Services Archive [LHSA], Edinburgh University Library [EUL], GD24, C6, D1 (10), Draft Document by C. Bennett, ‘AIDS in Lothian Case Study’, 1989.

a proposal for the provision of service to HIV-positive patients who, would soon require in-patient treatment.³ Brettle stressed that some of the HIV positive drug misusers he was treating had already started to show signs of AIDS-related illness.

Their proposal outlined short-term measures in order to deal with patients who might be admitted within the following twelve months. They recommended that two beds in each of the IDU's existing two wards be set aside for adult AIDS patients. This would provide separate facilities for homosexual and intravenous drug misusers suffering from AIDS, both of whom had shown a degree of intolerance towards each other in the past.⁴ Upgrading of the wards would be required as well as extra resources for out-patient facilities, equipment and staffing. The IDU consultants submitted their proposal to the LHB and without delay they agreed to provide a sum of £350,000 to cover the costs.⁵

The McClelland Report

The IDU consultants had also submitted a proposal for long-term care and treatment measures for AIDS sufferers. This included a separate purpose-built design attached to Pavilion 14 at the City Hospital's IDU to provide two new and separate wards.⁶ However, by this time, the issue of care and treatment of AIDS sufferers had become a national matter. The recent publication of the McClelland Report had predicted that the first AIDS cases in Scotland associated with intravenous drug misuse would occur

³ LHSa, EUL, LHB37/164, Infectious Diseases, Document, 'Provision of Facilities for the Care and Counselling of Patients with HIV Infection and AIDS', September 1986.

⁴ *Ibid.*

⁵ B. Pandering, '£350,000 to Care for AIDS Patients', *The Scotsman*, 26 September 1986, p. 7.

⁶ LHSa, EUL, LHB37/164, Document, 'Provision of Facilities for the Care and Counselling of Patients with HIV Infection and AIDS', September 1986.

in 1986 and by 1990, 144 new cases per year could be expected, the majority in Edinburgh.⁷ However, the Report recommended that further studies should be undertaken by a Working Group to establish the incidence rate of clinical AIDS and the resources required for the clinical care of these patients.⁸ Therefore, local arrangements were delayed until the outcome of the Working Group's findings in the summer of 1987. This will be discussed further in Chapter 7.

A Lothian Health Board Strategy

The McClelland Report had made a number of other recommendations. One of these was the need for Health Boards (HBs) to identify an appropriate individual 'to be responsible for co-ordinating action in connection with the AIDS epidemic, including both the prevention of infection and provision for the management of clinical disease'.⁹ The person assigned to this role for Lothian was George Bath. By the end of 1986, Bath had prepared a paper called 'A Strategy for Management of AIDS in Lothian', which was submitted to the Planning and Resources Committee of LHB.¹⁰ This outlined an overall objective to ultimately provide for AIDS in the same manner as other 'ordinary' health problems.¹¹ However, it was recognised that the predicted epidemic nature of the infection in Edinburgh, the uncertainty about routes of transmission, and the potential nature of spread, meant that an 'extra-ordinary response' was required in the interim.¹²

⁷ Scottish Home and Health Department, *HIV in Scotland – Report of the Scottish Committee on HIV Infection and Intravenous Drug Misuse*, (Edinburgh, September 1986), p. 7.

⁸ *Ibid.*, p. 15.

⁹ *Ibid.*, p. 1.

¹⁰ LHSA, EUL, GD24, C5, D3, (2.1.1) Lothian AIDS Advisory Group, Agenda and Minutes – Document, 'A Strategy for Management of AIDS in Lothian', 18 December 1986.

¹¹ *Ibid.*, p. 2.

¹² *Ibid.*

The paper focussed on four areas of concern; care and treatment, prevention of cross infection, prevention of infection in 'risk groups', and public information and education. Bath argued that the Board's activities in these areas required to be co-ordinated for maximum effect and needed to include close liaison with other agencies, both statutory and non-statutory. In order to achieve this, it was recommended that a team of Board Officers be created to include a community medicine specialist, a senior administrator, a senior nurse and a senior member of the Treasurer's staff.¹³

The paper also put forward detailed proposals for a campaign for the prevention of AIDS and for public education in Lothian, which would target those 'at risk' and the general public. The proposals stressed that the role of LHB in prevention of infection was a major one, but other agencies would also be included, necessitating extensive joint planning.

The need for HBs to encourage greater co-ordination and liaison with local authorities and the non-statutory sector in response to AIDS, was something that the MP for Edinburgh East, Gavin Strang, also emphasised in his Private Members Bill at Westminster. This led to the introduction of the AIDS (Control) Act 1987. Under the Act, HBs were required to submit annual reports updating the Government on AIDS/HIV statistics and their responses to AIDS. This would include reporting on action taken by all statutory and voluntary services in each locality, with an aim of encouraging or addressing any problems with joint working partnerships. The Bill was inspired by and reflected the sense of urgency felt in Edinburgh at this time.

¹³ *Ibid*, p. 6.

Berridge argues that the Act was a symbol of the ‘wartime emergency’ response to AIDS, where a national consensus had been reached in an attempt to co-ordinate services locally and nationally.¹⁴

To meet the LHB objectives, Bath outlined the need for additional resources totalling £221,000, which would cover the formation of an AIDS Team to focus on public education, and hospital services at the City Hospital’s IDU and the Genito-Urinary Medicine (GUM) Department at the Royal Infirmary.¹⁵ By the end of 1986, the additional resources had been approved by the LHB.¹⁶ These funds and those allocated to the IDU for extra beds for AIDS sufferers came to circa £570,000. This had not been provided directly by the SHHD from government AIDS expenditure funding.¹⁷ Rather, these costs had to be met from within the LHB’s own general budget, confirming the growing concern felt by the LHB about AIDS by the end of 1986. As mentioned in Chapter 5, this was at a time when financial cutbacks were being considered by the new management structure, which had been in place since the beginning of the year.

An Edinburgh District Council Strategy

Other statutory agencies began to express increasing concern by the end of 1986. The Environmental Health Director of the EDC, Richard Carson, began to compile a

¹⁴ V. Berridge, *AIDS in the UK: The Making of Policy, 1981-1994* (Oxford, Oxford University Press, 1996), pp. 121-2.

¹⁵ LHSA, EUL, GD24, C5, D3, (2.1.1) Lothian AIDS Advisory Group, Agenda and Minutes – Document, ‘A Strategy for Management of AIDS in Lothian’, 18 December 1986, p. 11.

¹⁶ *Ibid.* B3, Lothian Health Board, *AIDS in Lothian: Everyone’s Concern 1988 – A Report in Response to the AIDS (Control) Act 1987*. Report for Year Ending 31 March 1988, Section 2: Service Response, pp. 19-32.

¹⁷ NAS [National Archives of Scotland], HH61/1278, ‘Briefing Notes – Annex B – AIDS in Scotland’, November 1986.

document which addressed a city-wide strategy, which was aimed at filling in the gaps between national leaflets and television campaigns. A task force of 12 environmental health officials was planned, in order to co-ordinate a programme of meetings and seminars open to major employers in Edinburgh.¹⁸ The Chairman of the Environmental Health Committee, Councillor Ken Smith, told the *Scotsman* that:

We are all aware that AIDS is probably the most important health issue of our time, and possibly of our generation. We have to strive for a balance somewhere between total uncontrolled alarm and misunderstanding and a complacency that can lead to the risk of it being overlooked.¹⁹

Leaflets were to be distributed to food handlers, dispelling some of the myths surrounding AIDS and emphasising that there was no danger of infection if routine procedures were followed.

A Lothian Regional Council Strategy and the Formation of the Regional AIDS Group

Similarly, the Director of Social Work of the Lothian Regional Council (LRC), Roger Kent, recognised that a more formal strategy on AIDS was required for the provision of social and medical care for babies and other sufferers. In July 1986, Kent had submitted a report to the Social Work Committee seeking endorsement of the steps he had taken so far in responding to AIDS.²⁰ In addition to responding to the need to provide care for babies and counselling sessions for haemophiliacs, the Social Work Department (SWD) had been instrumental in providing information, guidelines and

¹⁸ LHSA, EUL, GD24, C5, D2, (2.2.0), Regional AIDS Group General (Part 1), Document, R. A. Carson, 'AIDS as a Communicable Disease – A Discussion Document and City Strategy', 1987.

¹⁹ M. Harker, 'City Task Force in AIDS Strategy', *Edinburgh Evening News*, 18 March 1987.

²⁰ NAS, ED39/476, Document, 'Acquired Immune Deficiency Syndrome (AIDS) – A Report by the Director of Social Work – No. 101: 1986/87', 31 July 1986.

training on AIDS to its staff. The Department had not adopted a general policy of screening clients. However, a different approach was adopted in the case of children admitted to foster care. Where it was known that a child was in a high-risk group, medical advice was sought about the need to test and inform carers.²¹

It would appear that, once the McClelland Report highlighted the potential number of cases of AIDS likely to develop in Edinburgh during the following year, the LRC began to respond. The SWD appointed an AIDS advisor and a social worker, David Taylor, who was seconded to the LRC's Chief Executive's Office as the Regional AIDS Co-ordinator.²² An AIDS Support Group (ASG) was created at the end of 1986 to help and advise the new Regional AIDS Co-ordinator, in order to prepare recommendations on a co-ordinated strategy and a policy statement on AIDS. The group consisted of members from the SWD, the LHB, the police, the Education Department and Edinburgh District Council. The ASG marked the beginnings of the first official inter-agency group, from within the statutory sector in Edinburgh to be concerned with the planning and coordination of services for AIDS.²³

In March 1987, a policy statement was published by LRC which made a total of 18 recommendations, including a commitment to continue to work closely with other agencies to ensure a co-ordinated approach to AIDS and to provide a range of facilities for the medical and social care of AIDS sufferers.²⁴ Also included was a commitment to provide adequate health education measures to combat AIDS.

²¹ *Ibid.*

²² C. Bennett and A. Pettigrew, 'Waiting for AIDS: The Response to HIV Infection in Lothian – Summary Report', (Centre for Corporate Strategy and Change, University of Warwick, 1989), p. 14.

²³ LHSA, EUL, GD24, C5, D3 (2.2.1), Regional AIDS Group, Agenda and Minutes (Part 2), Minutes of Meeting, 16 June 1987; AIDS Support Group – First Progress Report, 19 January, 1988.

²⁴ *Ibid.*, Regional AIDS Group, Agenda and Minutes (Part 1), Document, 'Policy and Resources Committee, LRC – AIDS Policy Statement, 1987'.

However, as will be shown in Chapter 7, a major obstacle would prevent the LRC from achieving some of these goals. This was finance. In discussions with the Social Work Services Group (SWSG), which was part of the Scottish Education Department (SED), at the end of 1986, the LRC indicated that their plans to cope with the AIDS problem would cost £300,000 annually. They were told that the formal position, which was that Local Authority provision for AIDS-related issues would have to be accommodated within public expenditure for 1987-88 and no exceptions would be made.²⁵

By the end of 1986, it is evident that local statutory agencies were beginning to respond with increasing concern to the potential problems associated with AIDS. However, the Scottish Office remained reluctant to contribute financially at this stage. Their lack of commitment to some aspects of AIDS policy is also evident below, in the context of a national media campaign, which highlights concerns about the moral tone of material.

Mass Media Campaign - 1987

The need for greater public education measures had become a matter of concern at the highest political level by the end of 1986. Berridge argues that pressure from various bodies within the government, media and policy community bodies contributed to defining and reinforcing the need for further action by politicians.²⁶ Norman Fowler, the Health Minister, had taken on the issue during a House of Commons emergency debate on 21 November 1986, he announced that £20 million would be made

²⁵ NAS, HH61/1278, Copy Draft Minute, SED to Minister of State, November 1986.

²⁶ Berridge, *AIDS in the UK*, pp. 102-7.

available to launch a major education campaign on AIDS.²⁷ This would include a further round of newspaper advertisements, a general poster campaign, a youth campaign and a leaflet drop to 23 million households in the UK. Fowler also announced that the importance of the task made it necessary to reconstitute the Health Education Council (HEC) into a special health authority with a 'clear line of accountability to Ministers and Parliament'.²⁸

The Scottish Office input into these decisions is significant since it confirms an ongoing reluctance to commit themselves to large scale education campaigns targeted at the general public. During discussions on the need to set up the public education campaign, John MacKay, Scottish Health Minister, wrote to William Whitelaw, the Deputy Prime Minister, to express his concern about the potential for criticism from the delivery of sexually explicit leaflets to every household. He suggested that professional experts on health education be brought in so that the Government could 'distance itself from possible criticism'.²⁹

Despite these concerns, the majority government view was that a pragmatic message was needed in the case of AIDS, rather than a moral one. The delivery of an education leaflet to every household, which included a message on 'safe sex', including condom use occurred in January 1987. To complement this, the Scottish Health Education Group (SHEG) began to take an increasingly active part in AIDS education in Scotland and had distributed two leaflets throughout local HB Education

²⁷ House of Commons debate on AIDS, *Hansard*, 21 November 1986, cols 801-2.

²⁸ *Ibid*, col. 803.

²⁹ NAS, ED39/476, Letter, J. MacKay to Viscount Whitelaw, 1 September 1986.

Departments and pharmacies.³⁰ One leaflet covered an introduction to the ‘AIDS Problem in Scotland’, while the second leaflet focussed on ‘AIDS and Sex – What Everyone Should Know’. The message was also one of ‘safe sex’, defined as faithfulness to one partner and the use of a condom as the best means of preventing HIV/AIDS.³¹

This material received strong criticism in Scotland, particularly from religious groups. Some felt that the messages did not go far enough in providing any moral stance that reflected Scottish ideology. For example, the Roman Catholic Church in Scotland claimed that the anti-AIDS campaign was ‘morally defeatist’ and decided to launch its own campaign announcing that it was wrong to use condoms irrespective of AIDS.³² Similar views were expressed at a meeting of Scottish Church Leaders, who produced a statement announcing that the government had a strong obligation to adopt a clear moral stance on AIDS.³³ One church leader stressed that society in Scotland expected the government to endorse moral principles on all issues including AIDS and believed that religious influence in Scotland made society’s expectations generally greater than elsewhere, particularly south of the Border where a greater diversity of attitudes existed.³⁴ Although some Scottish Ministers, such as MacKay, had also been concerned about the moral tone of the government’s message, the Scottish Office response to Church Leaders expressed the view that some members of society would

³⁰ See, NAS, SOE12/522, ‘SHEG News Release’, 27 January 1987. Copies of these leaflets can be found in the Health Education Board for Scotland Library, Canaan Lane, Edinburgh.

³¹ *Ibid.*

³² S. Robertson, ‘Church Goes it Alone in AIDS Battle’, *Scottish Sunday Mail*, 25 January 1987.

³³ NAS, HH61/1305, ‘Annex D, Copy Extract from Minutes of Church Leaders Forum’, 24 April 1987. The Church Leaders Forum was inaugurated in 1980. It was formed to replace the Church/State Partnership Committee. The forum’s members consisted of representatives from all the main churches in Scotland together with representatives from the Scottish Office.

³⁴ *Ibid.*

continue to indulge in sexual relations outside marriage and therefore a pragmatic approach, rather than a moral one, was appropriate.³⁵

Interestingly, Berridge notes that English Church Leaders were divided on the issue of AIDS education. Some were in favour of the government's line while others stressed the need for a firm moral position. As a result, there was no united action against the Government by the churches in England.³⁶ The relationship between the Church of Scotland and the Government during this period was particularly strained. The Church of Scotland was an outspoken critic of the Thatcher Government, especially on issues such as the poll tax, privatisation and unemployment. Indeed an attempt to convince the Kirk of the theological justification of her individualistic policies she subsequently attended an Assembly of the Church of Scotland, in 1988, but the whole episode was to prove hugely counterproductive.³⁷

AIDS Education in Schools

Another area of AIDS education that proved to be controversial was the provision of AIDS education in schools. The McClelland Report had recommended that:

It should be a high priority for the Scottish Education Department to ensure that information about AIDS and the transmission of HIV by needle sharing and by sexual contact should be built into the health education provided in schools.³⁸

³⁵ *Ibid*, Letter, M. Rifkind to The Rev. R. Waters, September 1987.

³⁶ Berridge, *AIDS in the UK*, p. 135.

³⁷ I. Swanson, 'Kirk's Still Preaching Politics 20 Years After Thatcher Row', *Edinburgh Evening News*, 15 May 2008, p. 12.

³⁸ Scottish Home and Health Department, *HIV In Scotland – Report of the Scottish Committee on HIV Infection and Intravenous Drug Misuse* (Edinburgh, September 1986), p. 14.

Following the Report, the new Scottish Health Minister, Lord Glenarthur, told a meeting of police and education chiefs that the government accepted the need to give education authorities and schools guidance on how to deal with AIDS and health education, but that this would require 'careful consideration'.³⁹ Interestingly, around the same time as the publication of the McClelland Report, a major drug-misuse education programme, which had been piloted in Strathclyde schools by the SHEG, the HEC and others, had received successful feedback. The 'Drugwise' programme was aimed at 12-14 year olds and avoided 'shock horror' tactics in favour of helping pupils reject offers of drugs, dissuade their friends from partaking and to be better informed about the range of drugs available. The government introduced 'Drugwise' selectively into schools in other regions. The programme was considered by some as an ideal vehicle for the inclusion of an AIDS-education element. However, this opportunity was not taken as civil servants at the Scottish Office felt that the risk of AIDS was not an appropriate theme for education directed at the prevention of drug misuse. The government claimed that drugs were widely misused by means other than injecting and therefore the case for drug education was much wider than the AIDS issue.⁴⁰

Thus, by 1987, little had been done at the Scottish Office level to address any gap in the education of young people, about AIDS, in Scotland, as recommended by the McClelland Report. In the spring of 1987 the issue was discussed by the House of Commons Social Services Committee. In a memorandum submitted by the Director of SHEG, it was claimed that there was 'no real infrastructure of health and social education in schools which carried a sex education programme to which AIDS [could]

³⁹ 'AIDS Alert in Schools', *Aberdeen Press and Journal*, 18 October 1986.

⁴⁰ *Ibid.*

be added'.⁴¹ At this time, England and Wales had introduced the 1986 Education Act (No.2), which placed a duty on school governing bodies to produce sex education policies that would encourage pupils to have due regard to moral considerations and the value of family life.⁴² The change was intended to strengthen parental influence over sex education at the school level in response to a back-bench campaign to allow parents the right to withdraw their children from sex education.⁴³

The SED were equally concerned about the moral content of sex education in schools. However, their response was that there was no need to create comparable measures for schools in Scotland because, sex education was taught within a broader programme of health and social education, north of the Border and there were no equivalent governing bodies for schools, nor was there any evidence of pressure from parents.⁴⁴ As Davidson's work has shown, there was also a strong history of reluctance on the part of the SED to issue firm guidelines on sex education in the belief that the initiative should come from individual schools.⁴⁵

The Social Services Committee also heard evidence from the Assistant Secretary of the SED who admitted that 'there was a need to do more to educate, to build education about AIDS into the curriculum at relevant stages'.⁴⁶ He claimed that the Consultative Committee on the Curriculum (CCC) and the SHEG were evaluating

⁴¹ House of Commons, Social Services Committee's Third Report, *Problems Associated with AIDS*, Vol. III, *Minutes of Evidence* (8 April – 13 May 1987) and *Memoranda* (London, March 1987), p. 174.

⁴² NAS, HH61/1278, Letter, D. J. Crawley to Secretary of State, 30 September 1986. See also, Berridge, *AIDS in the UK*, p. 194.

⁴³ NAS, HH61/1278, Letter, D. J. Crawley to Secretary of State, 30 September 1986

⁴⁴ *Ibid*, Letter, Secretary of State for Scotland to Secretary of State for Education and Science, 30 September 1986.

⁴⁵ R. Davidson, *Dangerous Liaisons: A Social History of Venereal Disease in Twentieth-Century Scotland* (Amsterdam, Rodopi, 2000) Ch. 12.

⁴⁶ House of Commons, Social Services Committee's Third Report, *Problems Associated with AIDS*, Vol. II, *Minutes of Evidence*, 4 February – 25 March 1987 (London, 1987), pp. 234-5.

health education in schools and the question of AIDS and sex education would be included.⁴⁷

The SED seemed reluctant to press ahead independently with national guidelines on AIDS education, and as a means of distancing themselves from such a sensitive issue, preferred to contribute £50,000, over a two year period, towards the cost of a project to be executed by Strathclyde Regional Council (SRC). This was designed to develop curricular guidelines on health education, which included AIDS and its prevention in the context of a carefully planned health education programme targeted at a range of age groups within schools.⁴⁸ Strathclyde contributed two-thirds of the cost. The project would also be carried out in consultation with the CCC and other agencies such as the SHEG.⁴⁹ It could be argued that this move to let SRC take the lead in national health education measures ensured that national guidelines would be produced without much cost to the SED and would prevent or mitigate any direct criticism of the Scottish Office over the issue of sex education or AIDS education.

Against this background of ongoing Scottish Office reluctance, Edinburgh agencies were driven to take the initiative and go it alone with a major campaign. This was known as the 'Take Care' Campaign and will be discussed in detail in Chapter 8.

The Supply of Needles and Syringes

⁴⁷ The Consultative Committee on the Curriculum was set up in October 1965 by the Scottish Office to advise the Secretary of State for Scotland on the development of the curriculum of primary and secondary schools.

⁴⁸ NAS, SOE14/129, AIDS Briefing Document, 10 April 1987.

⁴⁹ *Ibid.*

As discussed in the previous Chapter, whilst the Scottish Advisory Committee on HIV Infection and Intravenous Drug Misuse (SCHIIDM) had been sitting, tensions between the SHHD and the DHSS were rising over the issue of needle and syringe provision. The DHSS were under pressure to produce a position paper to their Chief Medical Officer (CMO) and Ministers, by mid September 1986, on the spread of AIDS both amongst injecting drug misusers and from this population to the general population.⁵⁰ This would allow for a decision on the supply of needles and syringes to be reached at the national level, ahead of the SCHIIDM's report, which was due to be published in late September. A copy of the DHSS's position paper was sent to the SHHD for comment. Some in the SHHD (particularly Covell who was a member of SCHIIDM) felt that the paper 'on balance' was good.⁵¹ However, its contents still appeared to be informed by an impression that the high incidence of HIV in the East of Scotland amongst drug misusers was peculiar and did not place a strong enough emphasis on drug misusers as the 'critical bridge' into the sexually active population at large.⁵² So even at this stage the risk of heterosexual spread was played down by the DHSS.

While these discussions were being raised at health department level, John MacKay made his views known publicly in an interview with the *Scotsman*, just prior to completion of the McClelland Report.⁵³ He stated that the government did not believe there was a demand for extra resources for AIDS, that sufferers should pay for their own treatment, that clean needles should not be distributed, that AIDS was a

⁵⁰ NAS, HH61/1125, Letter, E. Shaw, DHSS to A. Macpherson, SHHD, 27 August 1986.

⁵¹ *Ibid*, Minute, R. G. Covell to A. Macpherson, 9 September 1986.

⁵² *Ibid*.

⁵³ J. Smith and R. Wishart, 'AIDS 'Not a Special Case'', *The Scotsman*, 3 September 1986, p. 4.

straightforward moral issue and that the disease could be easily prevented by homosexuals and drug addicts changing their lifestyles.⁵⁴

The reaction to MacKay's interview caused considerable consternation for a number of individuals and pressure groups, especially in Edinburgh. Some felt it was an attempt to undermine the SCHIDM's report. Two members of the SCHIDM wrote directly to the Scottish Office. Brettle wrote that he was concerned that the Scottish Office was not taking the matter seriously enough, and that the article seemed to preempt the Committee's expert report.⁵⁵ Robertson wrote stating that,

Mr MacKay appears to have pre-judged the work and recommendations of the CMO's committee and has indicated that he has made certain decisions prior to the submission of that report ... The implication that nothing will be or can be done is contrary to prevailing medical opinion, and my own major interest, namely that of prevention, is dismissed with no apparent concern for facts or reality.⁵⁶

In addition, a number of objections were sent to the Scottish Office signed by individuals who appeared to form part of a group known as Capital Gay.⁵⁷ They demanded that MacKay apologise or be given the sack. The Scottish Homosexual Rights Group (SHRG) also called for MacKay's resignation, as did a Labour Spokesman on Scottish health, who claimed that the Minister had allowed his 'narrowminded, bigoted, nineteenth century prejudices to over-rule the considered

⁵⁴ *Ibid.*

⁵⁵ NAS, HH61/1296/1, Letter, R. Brettle to M. Rifkind, Secretary of State for Scotland, 12 September 1986.

⁵⁶ *Ibid.*, Letter J. R. Robertson to M. Rifkind, Secretary of State for Scotland, 6 September 1986.

⁵⁷ *Ibid.* It would appear that these cards were sent from a gay pressure group called, Capital Gay, who encouraged their supporters to write to the Scottish Office en masse with their objections. Unfortunately, some of the information on these has been redacted under the Freedom of Information Act (Scotland) 2002.

advice of his expert advisers [and this made] him unsuitable to hold any post in the Government'.⁵⁸

Not all responses to MacKay's interview were unfavourable. For example, one constituent wrote congratulating the Minister on his outspokenness and shared his opinion that AIDS was the responsibility of the individual, since it was 'caused by the wilful personal sexual lust in an un-natural vice and the sooner the males concerned understand they are courting death, the better'.⁵⁹ Another went so far as to suggest that the virus was caused by 'junkies and queers', who should all be screened, identified with AIDS tattooed on their foreheads and be locked away in a camp.⁶⁰ However, regardless of those in agreement with MacKay, it would appear that the negative reaction to his interview was the reason he was shifted from Minister of Health to Minister of Education in Scotland during a Scottish Office reshuffle shortly afterwards.⁶¹

Amongst the most controversial of recommendations in the McClelland Report was that relating to the supply of needles and syringes. As a matter of urgency the Committee recommended that:

Injecting drug misusers who cannot or will not abstain from misuse must be educated in safer drug taking practices. It is of the utmost importance that those who continue to inject are persuaded to use clean equipment and never to share it. Clean equipment should therefore not be denied to those who cannot be dissuaded from injection. In this connection authorities should be reminded that threat to life of the spread of HIV infection is greater than that of drug misuse.

⁵⁸ 'Calls for MacKay to Resign', *The Scotsman*, 6 September 1986, p. 5.

⁵⁹ NAS, HH61/1296/1, Letter to MacKay [personal information from respondent redacted under FOI (Scotland) Act, 2002].

⁶⁰ *Ibid*, HH61/1298/1, Letter to MacKay [all other information redacted under FOI (Scotland) Act, 2002.]

⁶¹ D. Scott, 'MacKay Gets Key Education Role', *The Scotsman*, 13 September 1986, p. 1.

On balance, the prevention of spread should take priority over any perceived risk of increased drug misuse.⁶²

Lord Glenarthur, stated that some time would be needed to assess the Report's recommendations, 'especially those relating to the possible issue of clean needles and syringes to intravenous drug misusers', because there were major implications for existing drug policy, which required measured consideration.⁶³

Meanwhile the SHHD remained concerned that the DHSS would press ahead independently with the introduction of free needles and syringe supply. To prevent this, the SHHD ensured that their views were fully represented at the appropriate DHSS meetings. Following one meeting, a further draft paper was drawn up, with which the SHHD were unhappy, because they felt their views had been ignored. One member of the SHHD staff was 'horrified' to read of the suggestion that seven syringes would be issued at once to a drug misuser.⁶⁴ In her view, 'if drug misusers [were] not prepared to come back daily, or if GPs [did] not want them to come back daily, then drug misusers would have to re-use the syringe'.⁶⁵

In the meantime, the SHHD sought the views of Scottish Ministers.⁶⁶ They told Ministers that, before any decision could be made to allow health authorities to provide drug misusers with free injecting equipment, careful thought would have to be given to the legal implications of 'aiding and abetting' a criminal act and to the implications for the government's present policy towards sufferers from diabetes

⁶² Scottish Home and Health Department, *HIV Infection in Scotland – Report of the Scottish Committee on HIV Infection and Intravenous Drug Misuse*, (Edinburgh, September 1986), p. 12.

⁶³ NAS, HH61/1126, Copy, Scottish Office Press Release, 24 September 1986.

⁶⁴ *Ibid*, Minute, P. A. Cox to A. M. Macpherson, 30 October 1986.

⁶⁵ *Ibid*.

⁶⁶ NAS, ED48/2203, Minute, A. Macpherson to Minister of State, 5 November 1986.

mellitus who had to pay for needles and syringes.⁶⁷ Ministers were also informed that the Scottish police had been effective in containing the drug situation, especially in Edinburgh, where the success in solving crime against traffickers and misusers had resulted in few new heroin addicts. The minute also indicated that informal soundings of police views indicated strong opposition to the proposed policy.⁶⁸

There were mixed feelings amongst those Ministers who replied. Most were against the idea of the provision of needles and syringes. One Minister, Ian Lang, stated he was 'inclined to resist the proposals to make clean needles and syringes available to hardened drug-users, but instead to do everything to strengthen the law enforcement campaign, coupled with heavy advertising on the drugs and AIDS fronts'.⁶⁹ Others stated that they were opposed but could be convinced otherwise on the basis of good evidence supporting a view that the policy would work.⁷⁰ Lord Glenarthur stated that AIDS was 'the most serious problem to have faced mankind in several generations' but further research would be needed to assess how needle and syringe provision might be implemented.⁷¹

The Office of the Lord Advocate of Scotland also commented on the Minute from the SHHD, and especially on the supply of clean needles and syringes in relation to common law in Scotland.⁷² Noted was that the legal implications were quite different in England and Wales, where the new Drug Trafficking Offences Act (1986) made it an offence to supply drug kits, except the supply of syringes and needles. It was felt

⁶⁷ *Ibid.*

⁶⁸ *Ibid.*

⁶⁹ *Ibid.*, Minute, I. Lang to Secretary of State for Scotland, 6 November 1986.

⁷⁰ *Ibid.*, Minute, Secretary of State to Minister of State, 5 November 1986.

⁷¹ *Ibid.*, HH61/1247, Minute, Minister of State to Secretary of State, 10 November 1986.

⁷² *Ibid.*, Minute, Lord Advocate's Department to Minister of State, 7 November 1986.

that this was a clear decision by the UK government not to penalise the provision of injecting equipment, because of the health risks if the supply were restricted.⁷³ In Scotland, as far as the common law crime of 'reckless conduct' was concerned, the Lord Advocate said he was not prepared to give a general and unqualified undertaking of immunity to doctors and pharmacists who supplied injecting equipment. Nonetheless, he did state that, if colleagues were in favour of such a policy, he would be prepared, in accordance with approved guidelines, to consider offering immunity in respect of a 'controlled' supply of needles and syringes to authorized doctors and pharmacists.⁷⁴

In a confidential minute to the Secretary of State for Scotland, the Secretary of the SHHD told Malcolm Rifkind that Scottish Ministers had expressed differing views, that progress had been disappointing on the part of the DHSS, since they had provided little opportunity for the existence of resolution of differences, and that the issue had even evoked differences between SHHD departmental officials.⁷⁵ As far as his own view was concerned, the Secretary confessed that he could not see how intravenous drug misusers who, refused to give up their habit, could be trusted to make use of clean equipment on their own. If the provision of needles and syringes was going to be approved, he would prefer that it be made a requirement that this should be done only under supervision.⁷⁶

Lord Glenarthur attended a meeting held at the DHSS on 18 November 1986. On the proposal to make needles and syringes available, the position of each health

⁷³ *Ibid.*

⁷⁴ *Ibid.*

⁷⁵ *Ibid.*, ED48/2203, Minutes W. K. Reid, SHHD to Secretary of State, 14 November 1986.

⁷⁶ *Ibid.*

department was still reserved but the general view was that, if an agreement on issuing the equipment could be reached, the preference was to issue free needles and syringes, rather than facilitating their purchase. Free issue via appropriate agencies would ensure that advice regarding prevention and drug misuse was provided at the same time and would keep drug misusers in contact with the authorities.⁷⁷ Lord Glenarthur told the meeting that early consultation with the Police and the Scottish General Medical Services Committee was highly desirable.⁷⁸

The following day Scottish Ministers had a meeting on the supply of needles and syringes.⁷⁹ In summing up the meeting, Rifkind, said that opinions were fairly evenly divided on whether the supply of needles and syringes would be beneficial or harmful. He felt the provision of needles to be 'distasteful' in principle, but said his final decision would take into account those directly involved with drug misusers.⁸⁰ It was agreed that, before any decisions could be made, it was necessary to get the views of the police and the medical profession.

Soon after, the SHHD arranged informal meetings with police and medical representatives. A meeting of the Association of Chief Police Officers (ACPO) (Scotland) failed to be convinced that the provision of clean injecting equipment would lead to a reduction in the spread of HIV infection.⁸¹ The contrary might prove to be the case. Police experience suggested that sharing needles was very much part of drug taking, especially for novices, and that the provision of clean needles would

⁷⁷ *Ibid*, HH61/1247, 'Summary of Note of Meeting on 18 November at 10.15am', 1986.

⁷⁸ *Ibid*.

⁷⁹ *Ibid*, SOE14/113, 'Meeting of Scottish Ministers – 9.00am Wednesday 19 November, 1986, Dover House'.

⁸⁰ *Ibid*.

⁸¹ *Ibid*, 'Preliminary Note on Main Points of Meeting on 24 November 1986 with Representatives of ACPO(S) to Discuss AIDS and Drug Misuse'.

make more needles available for sharing and access to such equipment might encourage others to take up injecting. Moreover, many drug misusers performed their habit in unhygienic and squalid conditions and showed little concern over infection compared with that devoted to 'getting their next fix'.⁸² The ACPO(s) did not believe that police practice would be affected if clean needles were introduced more widely. They said they would not relax their measures against drug taking. If a person were found to be in possession of clean injecting equipment and no drug this would not be confiscated. Confiscation would only occur if the equipment was of evidential value. The ACPO(s) also felt that the McClelland Report on police practices was inaccurate, being based upon evidence from the outwith the police. However, if Ministers did decide to make clean injecting equipment more readily available to drug misusers, they would not object.⁸³

The Chief Constable of Lothian and Borders Police reported to the Police Board in a similar vein in November 1986. He also noted that the McClelland Report had been compiled by persons from a medical background. Comments on police practice did not reflect the true procedures for taking possession of needles and syringes for evidential reasons, in Lothian, which were no different from those of other police forces in Scotland.⁸⁴ However, the Chief Constable agreed that, while police practice concerned itself with reducing illegal drug taking, the spread of AIDS was a major

⁸² *Ibid.*

⁸³ *Ibid.*

⁸⁴ LHSA, EUL, GD24, C5, D2, (2.2.0), Regional AIDS Group General (Part 1), Minute, Chief Constable, Lothian and Borders Police to The Clerk, Lothian and Borders Police Board, 4 December 1986. See also, D. Appleton, 'Scottish Office Rapped for 'Flawed' Report on AIDS', *The Scotsman*, 6 November, 1986, p. 8.

threat to public health. In this respect, the Lothian police were committed to playing its part in LRC's co-ordinated response to AIDS.⁸⁵

A meeting of the SHHD with representatives from Scottish General Medical Services and the Scottish Branch of the British Medical Association (BMA) also expressed misgivings about the introduction of free needles and syringes. It was stated that 'the composition of the McClelland Committee was slightly eccentric being made up of specialists of one kind or another' and did not reflect the general views of the medical profession.⁸⁶ In addition, it was noted that the research of Dr Roy Robertson, who had made clean needles available, had still to be completed and had not yet demonstrated the benefit of this practice. Their impression was that the sharing of dirty needles was part of the drug misusers' cult.⁸⁷ Like the police, doctors made the point that the drug addict was more interested in his next fix than in clean equipment.⁸⁸ They agreed that, if the government went ahead and supported the provision of needles and syringes, their first preference would be for this to be implemented at a Drug Dependency Centre. Their second preference was for authorized GPs (with special licenses from the Home Department) to deal with individual drug misusers. This would lessen the risk of the profession being exposed to police enquiries.

It is clear from the above evidence that there was strong opposition to the provision of free needles and syringes at all levels of decision-making in Scotland. Ministers,

⁸⁵ LHSA, EUL, GD24, C5, D2, (2.2.0), Regional AIDS Group General (Part 1), Minute, Chief Constable, Lothian and Borders Police to The Clerk, Lothian and Borders Police Board, 4 December 1986.

⁸⁶ NAS, HH61/1247, Letter, W. K. Reid to Secretary of State, 1 December 1986.

⁸⁷ *Ibid.*

⁸⁸ *Ibid.*

civil servants, the local police and the local medical profession were not in favour. Although a number of political, legal and financial implications were cited as reasons against taking this measure, all of these groups shared similar perceptions of drug addicts as reckless individuals whose behaviour was unpredictable and chaotic and whose misery was self-inflicted. Such perceptions played a significant part in shaping the attitudes of policy-makers towards the provision of injecting equipment and contributed to the delay in the Government's direct response to the McClelland Report in this regard.

However, by the end of 1986, the Government became subject to increasing pressure to respond to the issue. When challenged by Gavin Strang, during an emergency House of Commons Debate on AIDS on 21 November 1986, the Secretary of State for Social Services, Norman Fowler, announced that the Government was considering the matter 'seriously and urgently' and hoped to be able to make a decision soon.⁸⁹ It was noted that all opposition MPs present at the debate were in favour of needle and syringe provision.⁹⁰

The lack of response, from the SHHD, to the McClelland Report's recommendations was picked up by the Scottish press. In a newspaper article, McClelland told the *Scotsman* of his concern about the government's lack of response to his recommendations and hoped that there was more being done behind the scenes.⁹¹ As Berridge has argued, the AIDS policy community were prepared to use the press to be

⁸⁹ House of Commons Debate on AIDS, *Hansard*, 21 November 1986, col. 803.

⁹⁰ NAS, HH61/1278, Minute, P. A. Cox to Secretary, SHHD, 21 November 1986.

⁹¹ Chief Political Correspondent, 'AIDS Campaign goes Ahead before Decision on Needles', *The Scotsman*, 21 November 1986, p. 1.

openly critical of the government with the intention of stimulating action.⁹² In addition, the Independent Television News carried an interview with two Edinburgh prostitutes, one of whom claimed to be infected with AIDS but was carrying on with her trade and sharing needles. The same programme showed Roy Robertson with a supply of clean needles in a bid to prevent further infection.⁹³

At about the same time, a District Health Authority (DHA) in Peterborough made the decision to issue clean needles on an exchange basis at a special drug dependency clinic ahead of any government decision.⁹⁴ The specialist in Community Medicine who was responsible for initiating the scheme said needles would only be given to registered patients at a psychotherapy clinic for drug users. The initiative came from doctors and was approved by the DHA without the need for any backing from the DHSS. The SHHD feared that Scottish HBs might take similar action.⁹⁵ Thus, they urged Rifkind to agree that the Government approve the practice for some GPs to issue clean needles and syringes on a controlled one-for-one exchange basis, in accordance with guidelines to be issued by the CMO and to 'remind his colleagues that a decision to make clean needles more 'widely' available to drug misusers would be a step in the dark whose consequences cannot be predicted'.⁹⁶

Some Ministers and members of the House of Lords south of the Border were under pressure to change their views due to concern over the spread of AIDS. David Mellor, the Home Office Minister, claimed that, if it could be shown that giving

⁹² V. Berridge, 'AIDS, the Media and Health Policy', *Health Education Journal*, 50:4 (1991), pp. 182.

⁹³ Brief of programme in NAS HH61/1247, Minute, I. D. Williamson to Elgin and Secretary of State, 3 December, 1986.

⁹⁴ 'Addicts Offered Free Needles', *Independent*, 28 November 1986, p. 5.

⁹⁵ NAS, HH61/1278, Minute, P. A. Cox to Secretary, SHHD, 21 November 1986.

⁹⁶ *Ibid.*, ED48/2203, 'H(A) (86) 13 – AIDS and Drug Misusers', SHHD, 2 December 1986.

needles to addicts would stop sharing and stop the spread of AIDS, then he was in favour of it.⁹⁷ At a House of Lords Debate on AIDS on 10 December 1986, Lord Harris of Greenwich stated that he was in agreement with Mellor, because the availability of heroin determined the number of drug misusers, not the availability of needles.⁹⁸ Norman Fowler, was also in favour of issuing free needles.⁹⁹ Some Scottish MPs were still against the idea or yet to be convinced.

However, after a Special Cabinet Committee meeting on AIDS on 18 December 1986 it was announced that, based on recommendations in the McClelland Report, the Government intended to establish a number of special schemes in different parts of the UK, which would include the exchange of used needles and syringes and counselling.¹⁰⁰ The main aim was to generate information and the experience necessary in order to reach a conclusion as to whether access to clean injecting equipment would prevent the further incidence of HIV amongst intravenous drug misusers. Three of these schemes were envisaged for Scotland, in Dundee, Edinburgh and Glasgow.

The SHHD responded by holding further meetings with the police and the medical profession. Concerns amongst police officers were similar to before.¹⁰¹ Reassurances were given by SHHD that the authority to issue injecting equipment would lie only with doctors. It was also envisaged that the number of syringes and needles given out

⁹⁷ 'Minister Backs Calls for Free Needles', *The Scotsman*, 29 November 1986, p. 1.

⁹⁸ House of Lords Debate, *Hansard*, 10 December 1986, col. 1218.

⁹⁹ 'Addicts Offered Free Needles', *Independent*, 28 November 1986, p. 5.

¹⁰⁰ NAS, HH61/1248, 'Press Notice Issued Jointly by the DHSS and DES', 18 December 1986.

¹⁰¹ *Ibid*, HH61/1247, 'AIDS and Drug Misuse – Note of Meeting on 22 December 1986 to Discuss Proposals for Special Schemes for the Exchange of Needles and Syringes'.

at one time would be limited.¹⁰² Likewise, the Scottish BMA had similar reservations, as expressed at an earlier meeting but said they did not have any objections to those few GPs who were already issuing clean injecting equipment from participating in the schemes. They predicted that the majority of GPs would not wish to participate.¹⁰³

Edinburgh Needle Exchange

HBs in Tayside, Lothian and Greater Glasgow, representing Dundee, Edinburgh and Glasgow were invited to make proposals for setting up schemes. A meeting took place in January 1987 at the SHHD, where HBs outlined possible plans.¹⁰⁴ The Lord Advocate attended and gave his reassurances that registered medical practitioners who participated in the schemes would be immune from prosecution.¹⁰⁵ With respect to the plans for Edinburgh's needle exchange, LHB reported that two meetings, involving the police and social workers, had taken place.¹⁰⁶ The police stated that they would do what they could not to jeopardize the success of the scheme. However, they stressed that the law had remained unchanged with regard to the confiscation of injecting equipment. The Chief Administrative Medical Officer (CAMO) of LHB had also been in touch with the GP Sub-Committee of the Lothian Area Medical Committee, and was told that some GPs might be willing to participate in the scheme. However, GPs did not foresee being involved in the issue of injecting equipment because of its potential to disrupt surgeries. Rather, they envisaged a role for

¹⁰² *Ibid.*

¹⁰³ *Ibid.* Minute, P. A. Cox to J. Robson, 30 January 1987.

¹⁰⁴ *Ibid.* 'Note of Meeting – AIDS and Drugs Misuse, Meeting on 16 January 1987 in St Andrew's House, Edinburgh to Discuss Proposals for Special Schemes for Exchange of Needles and Syringes'.

¹⁰⁵ *Ibid.*

¹⁰⁶ *Ibid.*

themselves in counselling. The GP Sub-Committee also made it clear that they regarded the schemes as unscientific and were therefore sceptical.¹⁰⁷

At the GP grass-root level in Edinburgh, parallel concerns about drug misusers as being disruptive, unreliable and criminal were voiced. One GP was reluctant to become involved, in the scheme proposed, because he believed that drug addicts were all criminals who 'mug, shop lift, house break or prostitute themselves to gain enough money to pay a pusher for the mix of heroin, talcum powder, fertilizer or other adulterants that they intend to inject into themselves'.¹⁰⁸ Such extreme views were seen as destructive and unhelpful by advocates of needle exchange in Edinburgh, particularly by Infectious Disease Specialists, and reflected some of the differences of opinion within the local medical profession at the time.¹⁰⁹

The CAMO also stated that voluntary agencies were even less enthusiastic than GPs. Although many favoured the approach, as outlined in Chapter 2, 'they were unwilling to have their premises used for the exchange of needles or syringes', possibly through fear of police action.¹¹⁰ However, they envisaged a role for themselves in counselling drug misusers. Indeed, many were already carrying out this role and providing information on drug misuse and AIDS with funds provided by the SHHD. The Social Work Department at LRC offered their support but did not consider that counselling

¹⁰⁷ *Ibid.*

¹⁰⁸ I. McKee, 'AIDS and Heroin Abuse in Edinburgh, *Edinburgh Medicine*, 42 (1987), p. 3. See also, B. Christie, 'GP Criticises Free Needles Scheme', *The Scotsman*, 14 March, 1987, p. 5.

¹⁰⁹ *Ibid.*, 'More on Heroin Addiction and Intravenous Drug Misuse', *Edinburgh Medicine*, 43 (1987), p. 3.

¹¹⁰ NAS HH61/1247 'Note of Meeting – AIDS and Drugs Misuse, Meeting on 16 January 1987 in St Andrew's House, Edinburgh to Discuss Proposals for Special Schemes for Exchange of Needles and Syringes'.

from social workers should be a prerequisite for the issue of clean equipment, by doctors.¹¹¹

The LHB submitted their detailed proposal to the SHHD.¹¹² The new service was planned for the beginning of April 1987, would operate from Leith Hospital in North Edinburgh and be held once a week in the morning, for a period of 6 months, after which the SHHD and Ministers could assess its outcome. Those attending would be offered counselling and, where appropriate, offered a small supply of needles and syringes (up to a maximum of 3). The re-issuing of equipment would be on a one-for-one exchange basis, at which time further counselling would be given. The scheme would operate under the clinical responsibility of Dr Judy Greenwood, a Consultant Psychiatrist, and would be managed by her and George Bath. A Community Psychiatric Nurse would also support the clinic. Co-operation was anticipated from the Social Work Department and the police. It was estimated that, for a six-month period, the scheme would cost £8,324.

The CMO, Ian MacDonald, approved the LHB scheme subject to several conditions.¹¹³ First, the LHB were asked to bear in mind that the scheme would be limited to drug misusers in certain parts of the city. Secondly, the SHHD were uncomfortable with issuing three needles and syringes on a first visit. They suggested that drug misusers should be asked to hand in their own equipment beforehand. This should not be a prerequisite, but should nevertheless be encouraged. Thirdly, all schemes would be monitored and assessed centrally, in order to gather information

¹¹¹ *Ibid.*

¹¹² *Ibid*, HH61/1246, 'AIDS – Issue of Clean Needles to Drug Abusers – Experiment', 26 February 1987.

¹¹³ *Ibid*, Letter, I. S. Macdonald, CMO, SHHD to C. Brough, CAMO, LHB, 1 April 1987.

and identify changes in behaviour with respect to drug misuse and sexual practice. Finally, on the basis of these conditions, the SHHD said they were willing to meet the costs of the scheme.

On 9 April 1987, almost two years after the first study showed a high incidence of HIV amongst Edinburgh drug misusers, and amid much publicity and great reluctance on many fronts, the LHB needle exchange scheme opened its doors.¹¹⁴ Edinburgh was the first of the three schemes in Scotland to open. Dundee followed shortly after Edinburgh but Glasgow took much longer due to local opposition, which resulted in a change of location.¹¹⁵ It was considered essential by the SHHD to set up a scheme in Glasgow despite the incidence of HIV infection amongst drug misusers being much lower compared with Edinburgh and Dundee. However, it was believed that Glasgow would serve to enable comparisons to be drawn between areas of low and high incidence of infection.¹¹⁶

Substitute Drug Therapy

Another controversial issue, albeit with less publicity, was that relating to substitute drug therapy for drug misusers. The McClelland Report noted a range of opinions about the value of substitute therapy. However, the Committee recommended that:

Substitution prescription should be considered for those patients for whom it is judged that it will assist in reducing or stopping injection. It should also be

¹¹⁴ 'Doctor's Dilemma', *The Scotsman*, 9 April 1987.

¹¹⁵ NAS, HH61/1246, News Release – Scottish Information Office – 'AIDS and Drug Misuse', 2 April 1987.

¹¹⁶ *Ibid*, Minute, C. M. A. Lugton to Minister of State, 6 May 1987.

considered as a means of establishing and maintaining effective contact with injecting drug misusers.¹¹⁷

McClelland had gone on a fact-finding tour with respect to the treatment of methadone. This included Merseyside, where he was impressed with the NHS provision, which was based on a small number of multidisciplinary Drug Dependency Units, with a regional support team. The practice in Merseyside was to make maintenance therapy available to those, who would not commit themselves to detoxification.¹¹⁸ In a letter to the SHHD prior to his Report, McClelland stated that his impression as an outsider to the field was ‘that despite the tremendous controversy among drug specialists over the maintenance issue, it will prove to be an essential feature if we accept the prime goal of infection control’.¹¹⁹

Once the Report was published, the SHHD response was to propose further discussions with the medical profession about maintenance therapy because, in Scotland, the profession was not unanimous about the efficacy of maintenance therapy. Some members saw the practice as encouraging the drug misuser to continue from one year to the next without making any concerted effort to give up his/her habit.¹²⁰

As outlined in Chapter 2, Edinburgh psychiatrists had a long history of reluctance to prescribe substitute treatment (both heroin and methadone) for drug addiction, especially on a maintenance basis. However, little effort was made by the SHHD or

¹¹⁷ Scottish Home and Health Department, *HIV In Scotland – Report of the Scottish Committee on HIV Infection and Intravenous Drug Misuse* (Edinburgh, September 1986), p. 12.

¹¹⁸ See also, P. McDermott, ‘The Great Mersey Experiment – The Birth of Harm Reduction’ in J. Strang and M. Gossop (eds), *Heroin Addiction and the British System* Volume 1 (London, Routledge, 2005), pp. 139-56.

¹¹⁹ NAS, HH61/1126, Letter, D. B. L. McClelland to I. S. MacDonald, 14 July 1986.

¹²⁰ *Ibid*, ‘AIDS and Drug Misuse’ Draft, 14 October 1986.

the LHB to address this issue following the McClelland Report. Therefore, one medical practitioner, Ray Brettle, a non-psychiatrist, took the initiative to begin prescribing oral methadone to drug misusers with whom he came into contact. He took the decision as a means of not only preventing further infection of HIV by intravenous misuse but also of protecting those already HIV positive, since current research suggested a link between the frequency of injecting drugs and the progression to AIDS.¹²¹ Brettle claimed he was following a public health model of care.¹²² The decision made him unpopular with some of his medical colleagues in psychiatry and at the SHHD, since he was untrained in that particular field of medical expertise.¹²³ In addition, the SHHD had been concerned about his 'notification of addicts' procedures, or rather lack of them, with regard to out-patients.¹²⁴

Before long Brettle became known as 'Mr Methadone' as increasing numbers of drug misusers made their way to the City Hospital for a prescription.¹²⁵ However, by early 1987 his resources began to run short and he was told 'very forcibly' by the LHB to limit his prescribing to people who were HIV positive.¹²⁶ This type of policy soon came under heavy criticism from several sources. Brettle himself claimed that a number of his patients 'felt that they were infected with HIV as a result of that silly restriction on methadone prescribing', since this ensured they continued to inject.¹²⁷ Others suggested that the policy 'led to the invidious position of drug users attempting

¹²¹ R. Brettle, 'Did the Band Play On?', The George Bath Memorial Lecture, May 1996, p. 7.

¹²² *Ibid*, p. 6.

¹²³ *Ibid*. Although Edinburgh psychiatrists were reluctant to prescribe methadone some did see the treatment of drug misuse (mainly detoxification) as their domain.

¹²⁴ NAS, HH61/1125, 'Note by G. S. Thomson, SHHD on visit to see Dr R. Brettle on 2 December 1985'.

¹²⁵ S. Garfield, *The End of Innocence – Britain in the Time of AIDS* (London, Faber and Faber, 1995), p. 100.

¹²⁶ R. Brettle, 'Did the Band Play On?', The George Bath Memorial Lecture, May 1996, p. 7.

¹²⁷ *Ibid*.

to become HIV positive in order to receive methadone'.¹²⁸ As we shall see in Chapter 8, by 1988, little had changed and the policy of prescribing substitute therapy purely to HIV positive individuals came under further criticism from the Advisory Council on the Misuse of Drugs (ACMD) and prompted the establishment of a Community Drug Problem Service in Edinburgh that embraced methadone maintenance therapy for all drug misusers.

We can see from the above that, between the end of 1986 and mid-1987, the response to AIDS/HIV in Edinburgh was fraught with tensions at the local and national level over the controversial nature of policies in the fields of education and drug misuse. Although local statutory agencies such as the LHB and the LRC were instrumental in making new commitments in response to AIDS, by way of extra funding and the setting up of various groups to work towards a unified strategy in response to AIDS in the City, there continued to be opposition and reluctance to tackle areas of prevention most needed to curtail the spread of HIV/AIDS. Local doctors were just as guilty as the Scottish Office in resisting implementation of controversial policies such as changes in 'harm minimisation' approaches to drug misuse.¹²⁹ Although needle exchange schemes were set up in three Scottish cities, these were established under duress rather than agreement between the two government health departments. These tensions were the result of legal and financial differences between Scotland and the UK but also reflected a strong moral agenda in Scotland, at all layers of government, which was often presented in the Scottish press in order to further inflame debate.

¹²⁸ F. Watson, 'Models of Primary Care for Substance Misusers: The Lothian Experience', *Drugs: Education, Prevention and Policy*, Vol. 7, No. 3, 2000, p. 224.

¹²⁹ Harm minimisation has been defined as reducing harm to the individual and to society as whole, through prevention of the transmission of the virus. See, for example, V. Berridge, 'AIDS, Drugs and History', *British Journal of Addiction*, 87 (1992), pp. 363-70.

Although there were advocates of 'harm minimisation', particularly those Edinburgh based members of the SCHIDM committee, who saw this as a means of infection control, and those working directly with drug misusers, a strong moral agenda was also found at the local level. This was particularly so amongst the medical profession. Therefore, it would appear ironic and even paradoxical that in the City, which required the most immediate input to address the problem, delays were experienced on the basis of strong objection to a liberal drug policy on moral grounds.

PART THREE – THE RESPONSE TO AIDS IN EDINBURGH - 1987-1989

Part Three of this thesis deals with the period from the middle of 1987 to the end of 1989. Chapter 7 focuses on the period following the publication of the Tayler Report in May 1987.¹ This Report was compiled by a Scottish Home and Health Department (SHHD) Working Party set up to investigate the health service implications of HIV infection in Scotland. By concentrating on some of the recommendations outlined in the Report, this chapter will show the ways in which Edinburgh's response to AIDS, with regard to the provision of care and treatment for AIDS sufferers and of wider screening measures for pregnant women, continued to inform national policy. It will also reveal greater convergence between government departments in some areas of policy, such as mass media campaigns. Following this, Chapter 8 looks at developments within the field of drug misuse and education to highlight changes in the AIDS policy response towards a more liberal approach in Edinburgh, with the extension of the needle exchange scheme, a new Community Drug Problem Service (CDPS), which embraced methadone maintenance, and a local education campaign which provided free condoms as part of its initiative.

¹ Scottish Home and Health Department, *Report of the National Working Party on Health Service Implications of HIV Infection* (Edinburgh, May 1987).

CHAPTER 7 – THE RESPONSE TO AIDS IN EDINBURGH AFTER THE TAYLER REPORT - 1987-1989

This chapter discusses some of the recommendations in the Tayler Report, particularly those in relation to the provision of care and treatment to AIDS sufferers and antenatal screening for women. As these areas of response to AIDS were shaped to some degree by Edinburgh's specific experience of disease, this Chapter also serves to illustrate the ways in which local concerns became national issues. Attention is paid to the development of the Special AIDS Unit at the City Hospital, which was funded by the Scottish Home and Health Department (SHHD) and experienced a lengthy delay before it opened, due to financial concerns, anxieties over managerial changes within the National Health Service (NHS) and debates over the medical ownership of AIDS.

Attention is also given to the AIDS Hospice for Edinburgh, known as 'Milestone House', which was being developed at the same time as the Special AIDS Unit. The hospice became an inter-agency project, run jointly by the voluntary sector, the Lothian Regional Council (LRC) and the Lothian Health Board (LHB). Milestone House also suffered long delays in development. However, the reasons for these delays were the results of tensions between the local voluntary and statutory sectors over issues of control and responsibility for the project. The hospice was also delayed due to public opposition over its proposed location, which reflected wider public anxieties about drug misusers, over and above concerns surrounding their association with AIDS.

This chapter will also pay attention to the Tayler Report's recommendations for the testing and screening of pregnant women in Edinburgh and Dundee. This demonstrates that the incidence in Edinburgh of HIV amongst female drug misusers contributed to the decision to screen all pregnant women in Edinburgh. In addition, the introduction of these measures gave rise to debate over ethical issues.

The Scottish Working Party on Health Service Implications of HIV Infection

Although the Scottish Office remained reluctant to become fully immersed in controversial policies (such as those discussed in the last Chapter), by the end of 1986, substantial concern emerged over the resources which would be required to treat the numbers of patients with AIDS or AIDS related-illnesses, should projected increases prove accurate. As mentioned earlier, the McClelland Report had alerted the Government to potential increases in the number of AIDS cases in Scotland. However, these were crude estimates and the Report recommended that further studies should be carried out on the projected incidence of clinical AIDS and other HIV-related conditions and the likely resource requirements for the clinical care of these patients throughout Scotland.² This led to the establishment of a further SHHD Working Party specifically to investigate the health service implications of HIV.

The Chairman of the new Working Party was Winston Tayler, also the General Manager of LHB. Some LHB staff thought that Tayler's appointment was a 'little bit

² Scottish Home and Health Department, *HIV In Scotland – Report of the Scottish Committee on HIV Infection and Intravenous Drug Misuse* (Edinburgh, September 1986), p. 7.

odd' as it represented a departure from previous SHHD Working Party appointments.³ Traditionally, a medically-qualified Chairman was appointed, for example, a Chief Administrative Medical Officer (CAMO). Such an appointee would have previous experience of health service management.⁴ However, changes in the management structure of the NHS as a result of the Griffiths Report of 1983, had led to the introduction of General Managers from non-medical backgrounds who were made responsible for hospital boards.⁵ Tayler had been the first LHB General Manager with a non-medical background.⁶ The change provided the opportunity for the SHHD to appoint someone from a managerial background to the new Working Party. Within the SHHD, Tayler seemed the best choice because he was regarded as 'sensible' and was also responsible to the Scottish Health Board that faced most of the major problems connected with AIDS.⁷ As with the McClelland Committee, several members of the new Working Party were Edinburgh-based doctors or scientists (six out of twelve members). These included Ray Brettle and George Bath, both of whom had been members of the McClelland Committee.

Tayler himself welcomed the chance of chairing the Working Party as it gave him the opportunity to demonstrate his abilities as an effective manager at national level, whilst at the same time addressing Lothian's problem on AIDS.⁸ When the Working

³ LHSA [Lothian Health Services Archive], EUL [Edinburgh University Library], GD24, C6, D1 (10), Draft Document by C. Bennett 'AIDS in Lothian Case Study'.

⁴ *Ibid.*

⁵ See, Department of Health and Social Security, *NHS Management Enquiry Report*, Griffiths Report (London, DHSS, 1983). See also, J. Kinnaird, 'The Hospitals', in G. McLachlan (ed), *Improving the Common Weal – Aspects of Scottish Health Services 1900-1984* (Edinburgh, Edinburgh University Press 1987), pp. 213-75.

⁶ According to Bennett, Scotland was slow to respond to the Griffiths Report. Thus, LHB did not have its first General Manager until January 1986. For more details see, LHSA, EUL, GD24, C6, D1 (10), Draft Document, 'AIDS in Lothian Case Study'.

⁷ NAS [National Archives of Scotland], HH61/1277, Minute, H. Morison to A. Macpherson, 25 September 1986.

⁸ LHSA, EUL, GD24, C6, D1 (10), Draft Document by C. Bennett, 'AIDS in Lothian Case Study'.

Party completed its report in May 1987, a month ahead of schedule, it contained around 50 recommendations, covering a wide range of aspects relating to the AIDS problem, including projections for hospital services, care in the community, laboratory services, and nursing and dental services.⁹ It was thought that Tayler's practical involvement helped the Working Party to reach such early conclusions.¹⁰

The SHHD welcomed the early completion of their Report but were concerned about its publication pending the general election, which was scheduled for June 1987.¹¹ They had hoped to publish the Report after the election to avoid any political setback in the event of controversial findings. However, fearful that members of the Working Party might leak the Report to the media, the SHHD arranged for publication to go ahead. The Minister of State for Scotland was advised that the Report should be presented to the media by one of the Working Party members so that it would appear to have originated from an independent group of experts rather than the Scottish Office.¹² Copies were subsequently made available to Health Boards (HBs), the British Medical Association (BMA), other professional medical and dental bodies, voluntary organisations, churches and Directors of Social Work.¹³

The Tayler Report predicted that, by 1991, the incidence of new AIDS cases in Scotland would be circa 406 (projected 'best' estimate), making a cumulative total of

⁹ Scottish Home and Health Department, *Report of the National Working Party on Health Service Implications of HIV Infection* (Edinburgh, May 1987).

¹⁰ C. Bennett and A. Pettigrew, *Waiting for AIDS: The Response to HIV Infection in Lothian – Summary Report* (Centre for Corporate Strategy and Change, University of Warwick), 1989, p. 11.

¹¹ NAS, SOE12/524, Minute, C. M. A. Lugton to P. A. Cox, 7 May 1987.

¹² *Ibid*, Minute, C. M. A. Lugton to Minister of State, 14 May 1987.

¹³ *Ibid*, Document, 'Response by the Government to the Report of the Working Party on the Implications of HIV Infection for the Health Service in Scotland', 1987, p. 1.

983 cases.¹⁴ The majority of these would be in the South-East, West and Tayside areas of Scotland. In South-East Scotland, which included Edinburgh, these figures would be 179 and 400 respectively, the majority of whom would be intravenous drug misusers. On the basis of these figures the Working Party predicted that a total of 63 beds would be required for South-East Scotland.¹⁵

Special AIDS Units

On the basis of its predictions, the Tayler Report recommended that Special AIDS Units should be set up immediately in Dundee, Edinburgh and Glasgow where current HIV problems had been reported.¹⁶ These three cities currently had the most HIV-positive individuals and had experience of AIDS cases.¹⁷ Dundee was similar to Edinburgh due to the incidence of HIV amongst drug misusers. The Report concluded that the AIDS Units should be modelled on those currently operating in some London Hospitals and San Francisco. The dedicated Units were regarded as preferable to a 'scattered' model of care, where patients remain under the care of the doctor to whom they were first referred.¹⁸ However, the Report also stated that Special AIDS Units should not preclude the admission of AIDS patients to general wards when no AIDS Unit was available.¹⁹ In the section on the estimated overall revenue costs for the health service (including counselling, hospital services, support

¹⁴ Scottish Home and Health Department, *Report of the National Working Party on Health Service Implications of HIV Infection* (Edinburgh, May 1987), p. 31.

¹⁵ *Ibid.*

¹⁶ *Ibid.*, p. 6.

¹⁷ *Ibid.*, p. 47.

¹⁸ *Ibid.*, p. 41.

¹⁹ *Ibid.*

to voluntary agencies, hospices, community laboratories and dental bodies) the Report predicted that these would increase from £2.5m in 1987 to £11.5m in 1991.²⁰

The SHHD had considerable reservations about these costs. They felt the figures were badly presented, incomplete and poorly apportioned to individual Health Boards.²¹ Nonetheless, they agreed that Special AIDS Units for Glasgow, Edinburgh and Dundee were required and should be funded separately by the SHHD, in addition to normal HB allocated funds.²² The new Minister of Health for Scotland, Michael Forsyth, was advised accordingly. Forsyth had acquired his new position after the General Election of 1987 and was keen to ensure that any AIDS initiatives announced in Scotland would be in line with initiatives south of the Border. The SHHD confirmed that they had consulted the Department of Health and Social Security (DHSS) which had no comments on the proposals.²³ Thus, in July 1987, the SHHD announced that the Scottish Office was willing to make specific allocations to Lothian, Greater Glasgow and Tayside Health Boards to meet the capital and running costs for a fifteen-bedded Unit in Edinburgh, a fifteen-bedded Unit in Glasgow and a ten-bedded Unit in Dundee for the period 1988-1991.²⁴

Following the announcement, the three HBs were asked to submit detailed plans for their special AIDS Units. The Scottish Office made it clear that they saw no need for specially designed units. Rather, they favoured the upgrading of existing accommodation, which 'might come from within the present infectious diseases bed

²⁰ *Ibid*, p. 83.

²¹ NAS, HH61/1420, Draft Minute, C. M. A. Lugton to M. Forsyth, 29 June 1987.

²² *Ibid*.

²³ NAS, SOE12/524, Minute, I. D. Williamson to M. Forsyth and Secretary of State for Scotland, July 1987.

²⁴ *Ibid*, Scottish Office News Release, 'Government to Fund AIDS Units for Edinburgh, Dundee and Glasgow', 16 July 1987.

complement where there are low occupancy rates or beds are occupied by patients who could be accommodated in other wards'.²⁵ Provision within an existing IDU was in line with the long-term proposals submitted by Brettle to the LHB a year earlier, which entailed the development of Pavilion 14 at the City Hospital's IDU (see Chapter 6).²⁶ Brettle was an influential member of the Working Party's subgroup in this context, having previously presented in favour of specialist facilities.²⁷

The Edinburgh Special AIDS Unit

Some Edinburgh members of the Tayler Working Party had welcomed the early publication of the Report because they felt that, in the local context, time 'was slipping by while the epidemic [had] gained ground' and the long-term plans proposed by Brettle to provide medical care for AIDS patients needed to be implemented.²⁸ However, the LHB decided against Brettle's proposal at this stage and started to look at alternative options throughout the summer of 1987. This was seen as creating further delays and was a source of anxiety for staff at the IDU, who felt care and treatment should commence there as soon as was possible.²⁹ In a letter sent to the Unit General Manager (UGM) of the City Hospital, one IDU consultant said that there had been an increase in AIDS patients referred or admitted to the

²⁵ *Ibid*, Document, Response by the Government to the Report of the Working Party on the Implications of HIV Infection for the Health Service in Scotland', July 1987, p. 3.

²⁶ LHSa, EUL, LHB37/164, Document, 'Provision of Facilities for the Care and Counselling of Patients with HIV Infection and AIDS', September 1986.

²⁷ *Ibid*, GD24, C5, D4 (2.7.0.) National Working Party on Health Service Implications of HIV Infection, (Part 1), Minutes of First Meeting of Working Party, 12 December 1986 and Minutes of Second Meeting of Working Party, 26 January, 1987.

²⁸ *Ibid*, C6, D1 (10), Draft Document by C. Bennett, 'AIDS in Lothian Case Study'.

²⁹ *Ibid*.

Department and stressed the need for immediate help.³⁰ The response was a reassurance that plans were being drawn up.³¹

In the meantime, the SHHD had circulated a letter to all three HBs in August 1987, indicating that they would soon require details about the Special AIDS Units, but hoped that they had planning in hand.³² At the LHB, the letter raised the question of who was responsible for planning and compiling the LHB report. George Bath was the LHB's AIDS Team Co-ordinator and had assumed that he would be involved in the planning. He felt he had the right skills and experience for the job.³³ However, under the new NHS management structure there had to be a UGM to take control of the budget and be responsible for running the service.³⁴

By mid-October 1987, the same IDU consultant wrote another letter of concern to the UGM informing of a further increase in the number of AIDS patients and emphasising the need for urgent action.³⁵ Various options had been considered by the UGM, including the possibility of a site outwith the City Hospital. Finally, agreement was reached on the creation of a Unit from the City Hospital's Pavilion 14, exactly in line with the original submission by Brettle a year earlier.³⁶

However, by the time this decision was reached, only a few days remained before the SHHD's deadline for proposals. It became clear that the LHB's proposal was far

³⁰ *Ibid.* Letter quoted in text, July 1987 and part of confidential interview with C. Bennett.

³¹ *Ibid.*

³² LHSA, EUL, GD24, C6, D1 (10), Draft Document by C. Bennett, 'AIDS in Lothian Case Study'.

³³ *Ibid.*

³⁴ *Ibid.*

³⁵ *Ibid.*

³⁶ See, LHSA, EUL, GD24, B13, Lothian Health Board, *Hospital Services for HIV Positive Individuals - 1988-1991*, October 1987, p. 5.

from ready for submission.³⁷ At the last minute, Bath was asked if he and his AIDS Team could help to finalise the report.³⁸ As the SHHD had not provided a specific definition of what it meant by a Special AIDS Unit, Bath included out-patient care, community and psychiatric care, and data collection, which, along with the provision for in-patients, formed an integrated service for HIV/AIDS sufferers in the one location.³⁹

Once the proposal had been submitted and approved it was hoped that work would soon get under way. However, SHHD concerns over the Unit's costs which stood at £650,000, resulted in yet another delay. The amount was greater than that proposed by Glasgow for a similar Unit and led the SHHD to take steps to investigate costs further.⁴⁰ They asked the Building Division of the Common Services Agency (CSA) to analyse this. The CSA concluded that the plans submitted by the LHB were unsuitable for a conversion project and suggested an alternative plan for the building. Ironically, the alternative plan involved even greater costs than those originally estimated. The increase in capital costs to provide a Special AIDS Unit at Edinburgh now stood at £1.3m.⁴¹ Reluctantly, the SHHD agreed to meet the costs in full, especially since the LHB was the worst hit by the AIDS epidemic.⁴²

Soon after the SHHD agreed to the extra costs, the LHB discovered another problem which had resulted in an underestimation of almost a million pounds.⁴³ The SHHD

³⁷ *Ibid*, C6, D1 (10), Draft Document by C. Bennett, 'AIDS in Lothian Case Study'.

³⁸ *Ibid*.

³⁹ *Ibid*.

⁴⁰ C. Bennett and A. Pettigrew, *Waiting for AIDS: The Response to HIV Infection in Lothian – Summary Report*, p. 13.

⁴¹ *Ibid*.

⁴² *Ibid*.

⁴³ *Ibid*.

became extremely concerned about the financial implications of the project when a further approach was made to address this deficit. The Secretary of the SHHD was warned by a colleague that there was a 'potentially nasty situation with LHB over the AIDS Special Unit in Edinburgh, whose capital costs [had] risen very steeply'.⁴⁴ The SHHD were placed in a difficult position because they did not want to be blamed for any significant delay over the Unit.

Meanwhile, the LHB was growing increasingly concerned over the lack of beds for the care of AIDS patients and looked into the potential for expansion of hospital facilities in all Lothian acute hospitals. In its annual AIDS Report of 1989 the LHB suggested that, so far, Tayler's predictions of the cumulative number of AIDS cases in Lothian were fairly accurate.⁴⁵ The Report also warned that the 37 cases of AIDS seen so far in Lothian were 'only the tip of iceberg'.⁴⁶ The LHB AIDS Team had also carried out its own predictions on the number of new AIDS cases and the number of beds required for South East Scotland. Compared with Tayler's predictions up to 1991, these were slightly fewer. However, the LHB predictions extended to 1994 and these estimated (based on 'best' estimates) that, by then, the number of new AIDS cases would continue to increase to the point where 125 beds would be required for Lothian.⁴⁷ The Report noted the difficulty about making these predictions since they would be influenced by the development of effective treatments. These predictions were based on the absence of any effective treatment which would modify the course of the disease, allowing for less hospital in-patient care. Although AZT (Azidothymidine/Zidovudine) had been used at the City Hospital since 1987, some of

⁴⁴ NAS, HH61/1514, Minute K. J. Mackenzie to Secretary, SHHD, 7 July 1989.

⁴⁵ LHSA, EUL, GD24, B3, Lothian Health Board, *AIDS in Lothian: Time to Take Care - Report in response to AIDS (Control) 1987 Act* (LHB, Year Ending 31 March 1989), p. 4.

⁴⁶ *Ibid.*

⁴⁷ *Ibid.*, p. 38.

the patients suffered side effects and management was complicated by many patients being drug misusers, whose drug intake influenced treatment, thus making the impact upon hospital bed use unclear.⁴⁸

During these delays, ID specialists at the City Hospital became anxious about their precise role in the provision of care and treatment for AIDS patients, which they saw as increasingly under threat, particularly from other medical consultants at the Royal Infirmary who demanded additional resources for AIDS beds in their own wards. While IDU specialists accepted the need for general beds for AIDS sufferers in such hospitals, they felt strongly that such developments should be overseen by them as part of an integrated clinical plan.⁴⁹ Some IDU consultants believed that the care of AIDS and HIV sufferers required the development of a medical specialty, akin to those of neurology and nephrology.⁵⁰

However, the recent changes in the local NHS management structure meant that the City Hospital was managed separately from the Royal Infirmary of Edinburgh.⁵¹ Simultaneously, the LHB had cut back financially on several facilities and had carried out a number of hospital closures.⁵² Against this backdrop the only new money available from the LHB (via SHHD) appeared to be money for AIDS services. Thus it was no surprise that departments and consultants were in competition for this limited extra resource.

⁴⁸ R. Brett, *HIV – The Edinburgh Epidemic* (MD Thesis, University of Edinburgh, 1995), p. 221-9.

⁴⁹ LHS, EUL, GD24, C 2, D3 (2.28.0), 'AIDS and Drug Misuse Meetings', Letters, J. A. Gray, P. D. Welsby, R. P. Brett and C. L. S. Leen to I. A. D. Bouchier, 15 December 1989, R. P. Brett to W. Tayler, 8 January 1990 and R. C. Alabaster to E. McKie, 5 March 1990.

⁵⁰ *Ibid*, Letter J. A. Gray, P. D. Welsby, R. P. Brett and C. L. S. Leen to I. A. D. Bouchier, 15 December 1989.

⁵¹ *Ibid*, C6, D1 (10), Draft Document by C. Bennett, 'AIDS in Lothian Case Study'

⁵² C. Bennett and A. Pettigrew, *Waiting for AIDS: The Response to HIV Infection in Lothian – Summary Report*, p. 5.

Berridge argues that service development was part of the 'normalisation' of AIDS during this phase of policy response.⁵³ The 'Wartime Response' phase (between 1986 and mid-1987) that preceded it, had released funding and contributed to raising the profile of medical specialties, such as Public Health and Genito-Urinary Medicine (GUM).⁵⁴ In the national context, both these specialties benefited from AIDS, although GUM was the main beneficiary by this period.⁵⁵ In the Edinburgh context, both these specialties also benefited. The profile of Public Health had been raised with the allocation of funding to provide the new LHB AIDS Team, headed by Bath, the public health specialist. Bath's epidemiological work had contributed to both local and national policy due to his membership on the McClelland Committee and the Tayler Working Party. GUM had also benefited with extra funding provided at the end of 1986.

However, it would appear that, by the end of 1989, Infectious Diseases (ID) was the main beneficiary of AIDS in Edinburgh, especially with regard to increased resources for staff and accommodation. By the end of 1989, the Scottish Minister for Health had approved the increased capital costs identified for the Special AIDS Unit at the City Hospital.⁵⁶

⁵³ V. Berridge, *AIDS in the UK: The Making of Policy, 1981-1994* (Oxford, Oxford University Press, 1996), pp. 171-5.

⁵⁴ *Ibid.*

⁵⁵ *Ibid.*, 174.

⁵⁶ NAS, HH61/1524, Minute D. H. F. Dee to M. Forsyth, 31 January 1990.

Some have argued that ‘ownership’ of AIDS can be achieved through the efforts of clinical ‘product champions’ in medical departments.⁵⁷ This term is used by Bennett and Ferlie in their study of NHS responses to HIV/AIDS. They identified one key health authority clinical worker in any given area who was instrumental in raising the profile of AIDS in the public eye and had the potential capacity to drive forward proposals for service development.⁵⁸ For Edinburgh this product champion was arguably Ray Brett. Often a larger than life figure, speaking forcefully in broad regional dialect, known by his undergraduate students as ‘Metal Brett’, as well as being a well respected professional and academic figure, he was instrumental, from the early 1980s, in raising awareness of AIDS (especially via the press) as well as in shaping developments in response to AIDS within ID.⁵⁹ He was also an expert member of all the important SHHD AIDS related Committees and Working Parties and had influence upon national service developments. However, the rise in status of ID in Edinburgh was also helped by the high proportion of HIV positive cases occurring secondary to drug misuse, which had already led many Hepatitis B sufferers to the department, providing a ready made population.

The above demonstrates how initiatives that began with a local context, such as Brett’s original proposal to extend his wards for the care of AIDS sufferers, could become national concerns that in turn delay local advances in provision. However, the Edinburgh Special AIDS Unit was also delayed by the escalating costs to upgrade the IDU. The result was that by the end of 1989, Edinburgh was still without a Special AIDS Unit, despite the fact that such Units had been opened in Glasgow and Dundee.

⁵⁷ See, C. Bennett and E. Ferlie, *Managing Crisis and Change in Health Care* (Buckingham, Open University Press, 1994), p. 100.

⁵⁸ *Ibid.*

⁵⁹ Dale Garbutt, former undergraduate medical student.

As will be shown in Chapter 9, it was 1991 before the Edinburgh AIDS Unit finally opened.

AIDS Hospices

In addition to the Special AIDS Unit, other delays were experienced in relation to the development of an AIDS hospice in Edinburgh. However, these arose for very different reasons. The Tayler Report had recommended that two hospices, each with around fifteen places, should be established as soon as possible in Edinburgh and Glasgow.⁶⁰ The Working Party cited the model of hospice care proposed for Edinburgh by the Milestone Trust, which was a branch of the Scottish AIDS Monitor (SAM). Derek Ogg, SAM's Chairman and Edward McGough, had set up the Trust in 1986.⁶¹ At this time, it had become apparent to Ogg and McGough that the provision of hospice facilities would be vital for Edinburgh's large HIV-positive population. They envisaged a hospice providing sixteen places specifically for the care of AIDS sufferers, either on an intermittent basis, such as respite care, or on a longer-term basis.⁶² The Tayler Report also recommended that the hospices should have an outreach role in the community, providing support for patients living at home and also extending their counselling and support services to other AIDS patients and their families.⁶³

⁶⁰ Scottish Home and Health Department, *Report of the National Working Party on Health Service Implications of HIV Infection* (Edinburgh, May 1987), p. 8.

⁶¹ LHSa, EUL, GD24, C5, D4 (2.7.0), National Working Party on Health Service Implications of HIV Infection (Part 2), Note of Meeting held at St Andrew's House on 6 February 1987.

⁶² Scottish Home and Health Department, *Report of the National Working Party on Health Service Implications of HIV Infection* (Edinburgh, May 1987), pp. 63-4.

⁶³ *Ibid.*

In addition, the Tayler Report argued that dedicated AIDS hospices were appropriate for several reasons. First, existing nursing home and hospice funding might preclude the acceptance of AIDS patients. Secondly, the clinical expertise required would be different, especially with regard to the opportunistic infections found in AIDS sufferers. Thirdly, it was felt that an environment with predominantly older patients dying from cancer might not be the best place for a young person with AIDS and vice versa, particularly if there were management problems in relation to drug misuse.⁶⁴

The Tayler Report also recommended that the ‘successful management of AIDS in the community would require close collaboration between Health, Social Work, Housing, Voluntary and other agencies’.⁶⁵ These sentiments had already been expressed in Edinburgh by the Milestone Trust, as early as 1986, and also by the LRC. In its policy statement of March 1987, the LRC recommended that they should work closely with the LHB, the Edinburgh District Council (EDC) and voluntary organisations to establish ‘facilities for the medical and social care of people with AIDS, for people who have become infected, and for their families, friends and carers’.⁶⁶ The LRC’s interest at this stage had stemmed from current work on providing homes for HIV-positive babies.

As Berridge has noted, the same message was being spread throughout other parts of the UK at this time.⁶⁷ She argues that the Government’s emphasis on collaboration has to be understood in the context of wider changes in the NHS, such as the move towards a ‘Care in the Community’ model as outlined in the Griffiths Report on

⁶⁴ *Ibid*, pp. 64-5.

⁶⁵ *Ibid*, pp. 59-60.

⁶⁶ LHSA, EUL, GD24, C5, D4 (2.2.1) Regional AIDS Group – Agenda and Minutes, ‘Policy and Resource Committee – LRC – AIDS Policy Statement – 10th March 1987’.

⁶⁷ Berridge, *AIDS in the UK*, p. 168.

Community Care of 1988.⁶⁸ Similarly, other commentators have suggested that there was a tendency for the Government to encourage voluntary provision of health care since it supported the ideology that subscribed to the privatisation of the NHS and devolution of welfare provision from the statutory to the voluntary and private sector.⁶⁹

The need for a 'Care in the Community' approach was considered to be a matter of urgency in Scotland. The Tayler Working Party stressed that the high number of HIV-positive individuals who were drug misusers, were 'likely to be socially isolated, particularly when ill'.⁷⁰ The Scottish Office endorsed the Tayler Report's recommendation on hospices and considered the issue over funding to be a matter for HBs in the first instance, and that HBs should take account of the views of voluntary agencies.⁷¹ As will be shown from the history of the AIDS hospice in Edinburgh, tensions arose over issues of autonomy between the voluntary and statutory sector.

AIDS Hospice Care in Edinburgh – Milestone House

From 1986, the Milestone Trust had been successful in securing private resources from fund-raising events and covenants in an effort to secure hospice facilities for AIDS sufferers in Edinburgh. However, it became increasingly apparent that, in order to achieve its aims, public funding would be required. Informal discussions took

⁶⁸ Department of Health and Social Security, *Community Care: Agenda for Action*, (London, DHSS, 1988).

⁶⁹ J. Weeks, A. Taylor-Laybourn and P. Aggleton, 'An Anatomy of the HIV/AIDS Voluntary Sector in Britain', in P. Aggleton, P. Davies and G. Hart (eds), *AIDS: Foundations for the Future* (London, Taylor & Francis, 1994), p. 2.

⁷⁰ Scottish Home and Health Department, *Report of the National Working Party on Health Service Implications of HIV Infection* (Edinburgh, May 1987), p. 59.

⁷¹ NAS, SOE12/524, Document, 'Response by the Government to the Report of the Working Party on the Implications of HIV Infections for the Health Service in Scotland', p. 11.

place between the Trust and the LHB in October 1986 regarding a possible low rent for a LHB site.⁷² The LHB were interested in the project but did not have any suitable sites. The Milestone Trust also approached the Social Work Department at the LRC, whose support was secured together with the possibility of a financial contribution.

In early 1987, the Trust entered into talks with the SHHD in the hope of being offered financial support. One potentially suitable property at Pittendreich House in Lasswade, on the outskirts of Edinburgh, was discussed at this meeting. Derek Ogg told the SHHD that the LRC were interested in helping the project financially, to the tune of between £75,000-£90,000, but this had yet to be confirmed. It was anticipated by Ogg that the LHB would also be willing to help financially but they had not yet been formally approached.⁷³ In summing up the meeting, the SHHD informed Ogg that as far as they were concerned, the proposed hospice was a matter for the Trust and that, any funding from the NHS would have to come through the LHB, not the SHHD.⁷⁴ The same sentiments were expressed by the Scottish Office after the Tayler Report.

Soon after the SHHD meeting, Pittendreich House was deemed unsuitable for the Milestone Trust's purposes due to planning complications. Not dissuaded by the lack of public agency support, the Trust continued to explore possibilities for hospice accommodation. Before long another house in Balerno, on the western extremity of the city, was identified. However, before any further progress could be made, the

⁷² NAS, HH58/162, Document, 'Scottish Education Department – Social Work Services Group - AIDS – Proceedings of Seminar – 13 January 1987.

⁷³ LHSA, EUL, GD24, C5, D4 (2.7.0), National Working Party on Health Service Implications of HIV Infection, (Part 2), Note of Meeting Held in St Andrew's House, 6 February, 1987.

⁷⁴ *Ibid.*

house was badly damaged by a fire believed to have started under suspicious circumstances, causing further setbacks.⁷⁵

By this time, the LRC had become more interested in the issue of hospice care. As mentioned in Chapter 6, the LRC recognised in 1986 that its input should be directed towards the care of Edinburgh drug misusers and their babies, as many individuals lacked the usual social networks. In its AIDS Policy Statement of March 1987 LRC stated that:

There is a need to look at housing options to encourage independent living in the community with or without support. There is also the need to provide respite care facilities and to pursue the provision of a hospice in the Edinburgh area.⁷⁶

At an AIDS Support Group (ASG) meeting, various types of hospices, which could serve as a retreat for those diagnosed with HIV and contain nursing care for AIDS sufferers, were discussed.⁷⁷ One member argued that separate hospices would be needed for different risk groups, such as homosexuals and intravenous drug misusers. This was endorsed at a meeting of councillors, who passed a motion on the need for different kinds of hospices in Lothian. Paul Nolan, a Labour Councillor, told the meeting that at least six hospices, each accommodating 16 patients would be needed at a cost of £250,000 each and that the search was on for suitable buildings.⁷⁸ A major problem for the LRC was finance.⁷⁹ A memorandum by the Social Work Department (SWD) of LRC to the Social Services Committee, stated that the

⁷⁵ M. Harker, 'New Setback in Hunt for AIDS Home', *Edinburgh Evening News*, 4 March 1987.

⁷⁶ LHSA, EUL, GD24, C5, D4 (2.2.1) Regional AIDS Group – Agenda and Minutes, 'Policy and Resource Committee – LRC – AIDS Policy Statement – 10th March 1987'.

⁷⁷ *Ibid*, Minutes of Meeting, 16 June 1987, AIDS Support Group – First Progress Report, 19 January, 1988; *Ibid*, (2.6.1), Lothian AIDS Forum Agenda and Minutes (Part 1) – Draft - LRC – Lothian AIDS Forum Review, June 1988.

⁷⁸ A. McLean, 'All-Party Backing for AIDS Hospice Plan', *The Scotsman*, 18 February 1987, p. 6.

⁷⁹ C. Bennett and A. Pettigrew, *Waiting for AIDS*, p. 3.

‘Regional Council is in an adverse financial position greatly affected by Central Government’s policies’.⁸⁰ As mentioned in Chapter 6, the LRC had been informed that local authority provision for AIDS-related issues would have to be accommodated within public expenditure for 1987-88 and no exceptions would be made.⁸¹ Because the association between drug misuse and AIDS resulted in greater need the LRC felt that their funding allocations were inadequate.⁸² They were also concerned that any overspend on AIDS from their budget would incur penalties.⁸³

In addition to current funding concerns, there was a history of inadequate drug service provision at the local authority level. As outlined in Chapter 2, a Joint Working Party on Drugs Abuse (JWPDA) in Lothian had been set up in 1983 on the initiative of the LRC. Part of its remit was to gather information on existing problems in areas, where there had been a high incidence of drug abuse, and to examine the implications for policies and practice.⁸⁴ However, other than two reports by the JWPDA on drug misuse, one of which had recommended that urgent action be taken to provide a short stay community based drugs crisis centre, the lack of money and ‘the feeling that drug misuse was properly a problem for the health service’, had meant that little had been done to address the issue of drug misuse services by the LRC by the second half of the 1980s.⁸⁵ Clearly, a mixture of both voluntary and public funds (including health

⁸⁰ House of Commons, Social Services Committee, Third Report, *Problems Associated with AIDS*, Vol. II, Minutes of Evidence (4 February – 25 March 1987), pp. 203-10.

⁸¹ NAS, HH61/1278, Copy Draft Minute, SED to Minister of State, November 1986.

⁸² House of Commons, Social Services Committee, Third Report, *Problems Associated with AIDS*, Vol. II, Minutes of Evidence (4 February – 25 March 1987), pp. 203-10.

⁸³ NAS, HH58/162, ‘Scottish Education Department – Social Work Services Group – AIDS – Proceedings of Seminar – 13 January, 1987.

⁸⁴ LHSA, EUL, GD24, B3, Document, ‘Joint Working Party on Drug Abuse in Lothian, Progress Report’, (Lothian Regional Council, 1984), p. 3.

⁸⁵ *Ibid*, C6, D1 (10), Draft Document by C. Bennett ‘AIDS in Lothian Case Study’; Lothian Regional Council, *Drug Action in Lothian, Progress – Report of Joint Working Party on Drugs Abuse in Lothian*, (Lothian Regional Council, 1986), p. vi.

service contributions) were needed in order to achieve AIDS hospice provision in Edinburgh.

The Chief Executive of the LRC recommended that the ASG should oversee the Council's motion and it was agreed that meetings should be organised to include representatives from the LHB and the voluntary sector in order to encourage joint collaboration, as outlined in the LRC's policy statement.⁸⁶ By April 1987 the ASG began to hold separate meetings with non-statutory agencies to explore ways of working together in the fight against AIDS. This led to the formation of the Lothian AIDS Forum (LAF), which was comprised of people at grass-root level, who were engaged in education and prevention, and in direct contact with people infected or affected by HIV or AIDS. LAF was chaired by the LRC's Regional Co-ordinator for AIDS, David Taylor. A meeting in the Summer of 1987 recommended that two representatives from the voluntary sector should become members of the ASG.⁸⁷ This marked the official beginnings of joint collaborations between the voluntary and statutory sectors and by the Autumn of 1987, voluntary group membership of the ASG had increased to four. At the same time, the ASG became known as the Regional AIDS Group (RAG). These collaborations were formed before the Tayler Report published its recommendation on joint working between the two sectors. It would appear that Edinburgh's experience did influence the Tayler Report in this respect.

In the meantime, the Milestone Trust had pressed ahead with attempts to find a suitable property for a hospice. They approached the LRC about properties that might

⁸⁶ *Ibid*, C5, D2 (2.2.1), Regional AIDS Group, Agenda and Minutes (Part 1), Minutes of Meeting, 9 March 1987.

⁸⁷ *Ibid*, Minutes of Meeting, 16 June 1987.

be surplus to the Council's requirements. The LRC invited the Trust to investigate a council property at Wallhouse in Torphichen, West Lothian.⁸⁸ The spring edition of *Gay Scotland* in 1987 announced that the Milestone Trust had bought its first hospice for AIDS sufferers which was going to be located in large leafy grounds outside Edinburgh, but within easy reach of the City.⁸⁹ However, this plan fell through amidst strong opposition from Torphichen residents, reinforced by concerns over the excessive costs projected for the adaptation of the property. Comments from residents, including a doctor, ex-social worker and teacher, suggested that some of the anti-hospice campaigners were resentful of LRC taking decisions without sufficient consultation with the community. The 'City was passing the buck' in their eyes.⁹⁰ In August 1987, the Milestone Trust formally withdrew its interest in Wallhouse.⁹¹

By the autumn of 1987, the RAG had produced a document on a proposed approach to hospice provision.⁹² This recommended that a Working Group be created, on which the LHB, LRC and the voluntary sector would be represented.⁹³ Ten members were recruited, four from the LRC, four from the LHB and two from the voluntary sector, including Derek Ogg and a project leader from the Leith Drug Group.⁹⁴ The Working Group held a series of meetings from November 1987 to February 1988 at which the planning of a hospice was discussed at length. A number of issues were raised in their Report of March 1988.

⁸⁸ *Ibid*, B16, Lothian Regional Council, *Residential Needs of People with AIDS – Report by Working Group*, March 1988, p. 3.

⁸⁹ 'Milestone Lift-Off', *Gay Scotland*, 32 (March/April 1987), p. 5.

⁹⁰ 'Torphichen – A New Byword for Bigotry', *Community Care Magazine*, 20 August 1987, p. 9. See also, 'Milestone Update', *Gay Scotland*, 35 (September/October 1987), p. 5.

⁹¹ LHSA, EUL, GD24, B16, Lothian Regional Council, *Residential Needs of People with AIDS – Report by Working Group*, March 1988, p. 3.

⁹² *Ibid*, C5, D2, (2.2.1) Regional AIDS Group, Agendas and Minutes (Part 1), Document, 'AIDS Support Group – Hospice Provision – Proposed Approach', 19 October 1987,

⁹³ *Ibid*.

⁹⁴ *Ibid*, B16, Lothian Regional Council, *Residential Needs of People with AIDS – Report by Working Group*, March 1988, Appendix 1.

As Lothian's high rate of HIV infection occurred amongst both male and female drug misusers, an argument was made in favour of a hospice, which could accommodate residents of both sexes and possibly their children.⁹⁵ At this time there were no other AIDS hospices in the UK, although two were planned in London, mainly to provide care for homosexual men.⁹⁶ The Working Group also felt that a new hospice had to take account of prejudices that existed between homosexual men and active drug users, possibly by providing separate accommodation facilities. It was also recognised that, as the majority of HIV/AIDS sufferers would come from disadvantaged areas of the city, access for patients and families would need to be available and affordable. Therefore, it was proposed that residential facilities should be concentrated within Edinburgh.⁹⁷ Finally, it was predicted that the financial costs for such a project would be significant in terms of capital and revenue expenditure. The Working Group noted that, although adapting an existing building would be less expensive, this would prove difficult. Only a new build hospice would meet Lothian's special needs.⁹⁸

From the above it is clear that the issue of provision of hospice care for AIDS sufferers was becoming increasingly complex and important to both voluntary and statutory agencies in Edinburgh, before the recommendations outlined in the Tayler Report. However, while steps had been taken to encourage collaborations between the two sectors, by 1988 tensions were beginning to rise over issues of autonomy.

⁹⁵ *Ibid*, p. 2.

⁹⁶ *Ibid*.

⁹⁷ *Ibid*, p. 4.

⁹⁸ *Ibid*, p. 21.

In early 1988, the Milestone Trust submitted an application to the RAG to fund a Development Officer for a period of six months to oversee the planning of a new hospice. By this time a large amount of money, totalling around £400,000 over a four-year period, had been offered to the LRC by the Monument Trust, who were part of the Sainsbury Trust.⁹⁹ The Monument Trust had money available to help organisations fund work related to HIV/AIDS and were keen to extend their sponsorship to Scotland.¹⁰⁰ They stated that they wanted to assist statutory agencies to realise their agreed strategies and would only provide grants to voluntary agencies on the LRC's recommendation.¹⁰¹ The Chief Executive of the LRC conferred this responsibility onto the RAG, which considered several applications from the voluntary sector.¹⁰²

The Milestone Trust's application was rejected by the RAG, who took the view that the Trust's plans to build a hospice would take longer than six months. Others in the statutory sector had reservations about the project design because they felt it had been drawn up with the gay community in mind, rather than intravenous drug misusers.¹⁰³ This resulted in a setback for the Milestone's Trust developments in the field of hospice provision and created tensions between themselves and the Local Authority.

By the end of 1988, the Milestone Trust had faced a further reverse in its plans to establish and maintain principal control of an AIDS hospice in Edinburgh. On the

⁹⁹ *Ibid*, C5, D3 (2.2.1) Regional AIDS Group Agenda and Minutes (Part 3), Letter, A. J. Thomson to Members of RAG, 17 June 1988.

¹⁰⁰ *Ibid*, D2 (2.2.0), Regional AIDS Group (Part 1), Letter, R. G. Musgrave to G. Bath, 20 November 1987.

¹⁰¹ *Ibid*, D3, (2.2.1), Regional AIDS Group Agenda and Minutes (Part 3), Letter G. Lomas to D. Taylor, 23 August 1988.

¹⁰² *Ibid*, (Part 2), Minutes of Aids Support Group, 1 December 1987.

¹⁰³ C. Bennett and A. Pettigrew, *Waiting for AIDS*, p. 15.

first 'World AIDS Day', 1 December 1988, the LRC and the LHB announced the launch of 'The Waverley Care Trust' (WCT), a charitable organisation, whose purpose was to establish a residential facility for people with AIDS in Edinburgh.¹⁰⁴ This presented the Milestone Trust with a dilemma: whether to carry on themselves without funding from the statutory sector, or agree to become one of the trustees of the new body.¹⁰⁵ They chose the latter, and Derek Ogg became one of seven trustees, the majority of whom were from the statutory sector.¹⁰⁶ The new Director of WCT was Roger Kent, who had retired as Director of Social Work at the LRC to take up this new role, which was salaried. This was in contrast to the Milestone Trust, which had been formed and managed by unpaid volunteers who were part of the original policy community in Edinburgh, responsible for the foundation of SAM. As Berridge has shown, this period of the response to AIDS in the UK was characterised by a shift from voluntary posts to paid professional posts.¹⁰⁷

By setting up a new Trust, the statutory sector was able to retain a degree of control over where and how an AIDS hospice would be built in Edinburgh, whilst simultaneously relying on private funds to do so. However, in recognition of the contribution made by the Milestone Trust, it was agreed that the hospice would be known as 'Milestone House'.¹⁰⁸ This gesture did little to alleviate growing tensions between voluntary and statutory sectors. Indeed, it would appear that these tensions were a microcosm of wider friction between the voluntary sector and those in the statutory sector, particularly in relation to financial matters. For example, at a RAG

¹⁰⁴ *Ibid.* See also LHSA, EUL, GD24, C5, D4 (2.6.1), Lothian AIDS Forum Agenda and Minutes (Part 1), Minutes of RAG, 23 November 1988.

¹⁰⁵ C. Bennett and A. Pettigrew, *Waiting for AIDS*, p. 15.

¹⁰⁶ LHSA, EUL, GD24, B3, Lothian Health Board, *AIDS in Lothian: Time to Take Care - Report in response to AIDS (Control) 1987 Act* (LHB, Year Ending 31 March 1989), p. 55.

¹⁰⁷ Berridge, *AIDS in the UK*, p. 155.

¹⁰⁸ C. Bennett and A. Pettigrew, *Waiting for AIDS*, p. 15.

meeting in September 1988, voluntary sector representatives expressed concern over the prioritising exercise that had been in place to determine the expenditure of funding from the Monument Trust.¹⁰⁹ Many in the voluntary sector felt they were unfairly represented and had little say over matters of funding. Similarly, within the Health Service, staff involved in a drug project in Edinburgh, whose funding and oversight was handed over from the SHHD to the LHB in 1987, threatened to take industrial action over alleged funding reductions.¹¹⁰

In the UK context of relationships between voluntary and statutory groups in relations to AIDS, Weeks, Taylor-Laybourn and Aggleton noted a shift between the two by the late 1980s, from a picture of happy collaboration to one of ambiguity.¹¹¹ Similarly, Berridge claims that the voluntary ethos of pure self-help, gave way to a relationship where the boundaries between the voluntary and statutory became blurred and resulted in a 'perceived marginalization' for some voluntary groups.¹¹² In the next part of this thesis it will be shown how the tensions between the voluntary and statutory groups became increasingly complex and intense by the early 1990s.

These tensions did not stand in the way of WCT's progress in establishing hospice facilities. Efforts were made to raise funds from the LHB, the EDC, the LRC and

¹⁰⁹ LHSA, EUL, GD24, C5, D4 (2.6.1) Lothian AIDS Forum Agenda and Minutes (Part 1), Regional AIDS Group Minutes, 27 September 1988.

¹¹⁰ NAS, SOE12/521, Minute J. Gilmour to M. Forsyth, 31 October 1989.

¹¹¹ J. Weeks, A. Taylor-Laybourn and P. Aggleton, 'An Anatomy of the HIV/AIDS Voluntary Sector in Britain', in P. Aggleton, P. Davies and G. Hart (eds) *AIDS: Foundations for the Future* (London, Taylor & Francis, 1994), pp. 1-19.

¹¹² V. Berridge, "'Unambiguous Voluntarism?'" – AIDS and the Voluntary Sector in the United Kingdom, 1981-1992', in C. Hannaway, V.A. Harden and J. Parascandola (eds), *AIDS and the Public Debate: Historical and Contemporary Perspectives* (Amsterdam, Oxford, Tokyo, Washington D.C., IOS Press, 1995), pp. 153-69.

charitable contributions, including a grant from the Monument Trust.¹¹³ By the summer of 1989, over £1,000,000 had been raised.¹¹⁴ The LHB offered a site in the grounds at the southwest of the City Hospital for the proposed hospice.¹¹⁵

As with previous attempts at securing a site for an AIDS hospice, a great deal of opposition came from the local community. Several letters of protest from local residents and councillors were sent to the General Manager of LHB and copies were also forwarded to the Secretary of State for Scotland.¹¹⁶ Some residents were concerned about the exposure of local communities to hospice visitors, who may be drug misusers. Fears were raised about discarded needles, possible muggings and house break-ins, and the potential for local school children from the school adjacent to the hospital boundary to be encouraged to take drugs.¹¹⁷ The Scottish press played its role in reinforcing fear and anxiety over hospice provision. The *Edinburgh Evening News* reported that protestors had compiled a petition containing a thousand names. The Chairman of the Firrhill Residents' Action Group stated that local people were not just 'opposed to the proposed site of the hospice, many [were] against the whole concept'.¹¹⁸

In response to these letters of concern from residents, the Secretary of State stated that the LHB would consult extensively and look closely at local views, taking these into

¹¹³ LHASA, EUL, GD24, C5, D3 (2.2.1), Regional AIDS Group Agenda and Minutes (part 4), Minutes of Lothian AIDS Forum, 19 December 1989. See also, *Ibid*, C 2, D3 (43.1.1) Planning and Resources Committee Minutes (Part 1), Draft Minutes of Planning and Resources Committee, 22 June 1989.

¹¹⁴ 'Residents Step Up AIDS Hospice Fight', *Edinburgh Evening News*, 31 July 1989, p. 1.

¹¹⁵ LHASA, EUL, GD24, C5, D3 (2.2.1), Minutes of Lothian AIDS Forum, 27 June 1989. See also, *Ibid*, C2, D3 (43.1.1) Planning and Resources Committee Minutes (Part 1), Draft Minutes of Planning and Resources Committee 22 June 1989.

¹¹⁶ NAS, SOE12/253, Letter, M. Rifkind to J. Allan, 21 July 1989.

¹¹⁷ *Ibid*, SOE12/251, Letter to M. Rifkind, June 1989. [Name of residents extracted under Freedom of Information (Scotland) Act 2002.]

¹¹⁸ 'Residents Step Up AIDS Hospice Fight', *Edinburgh Evening News*, 31 July 1989, p. 1.

account before any decisions were made.¹¹⁹ The WCT was determined to push ahead with the proposed site at the City Hospital. Kent stressed the urgency and need for such a facility, pointing out that, by 1994, 575 AIDS sufferers would be living in Edinburgh.¹²⁰ In July 1989, a meeting took place between the Secretary of State and representatives of the WCT, which included the Lord Provost of Edinburgh in her capacity as one of the Trustees. Kent informed the Scottish Office that 50 per cent of drug takers were no longer injecting and indicated that the Parents' Association and the Janitor of the local school were supportive.¹²¹ As a compromise, the Lord Provost suggested that the original location of the site for the hospice be moved elsewhere within the City Hospital grounds so that it would cause less concern to residents.¹²² As with the Special AIDS Unit, it would be a further two years before the building finally opened.

By concentrating on the efforts an AIDS Hospice in Edinburgh this chapter has demonstrated that some of the ideology behind its establishments, such as collaboration between the voluntary and statutory sector were already in situ in Edinburgh, before the Tayler Report was published. Indeed, Edinburgh's influence on the Report has been shown through its membership and the adoption of the Milestone Trust's model of care as an example for other hospices in Scotland. The process of establishment of a hospice in Edinburgh also revealed changes in the relationship between these two sectors, showing that by the end of 1989, the relationship had become complex and sometimes bitter. Tensions had developed between some of the early volunteers and the statutory sector and, at the same time,

¹¹⁹ NAS, SOE12/253, Minute, C. M. A. Lugton to M. Forsyth and M. Rifkind, 25 August 1989.

¹²⁰ R. Edwards, 'Future Shock – Edinburgh is on the Verge of an AIDS Explosion', *New Statesman and Society*, 14 July 1989, pp. 22-3.

¹²¹ NAS, HH61/1219, Minute U. Jamieson to G. W. Tucker, 24 July 1989.

¹²² *Ibid.*

aspects of the voluntary sector took on a more formal aspect, exemplified by paid posts, which were open to and often filled by former statutory sector employees.

Antenatal Screening

The Tayler Report rejected the need for widescale screening of the general population for purposes of health maintenance.¹²³ Until effective treatment for HIV infection became available, the Report did not see the need for screening at this level. However, wider screening measures for antenatal women were considered differently. The Report recommended that research be undertaken to establish if wider screening measures should be adopted for all antenatal women.¹²⁴ As mentioned in Chapter 5, there were already some in favour of using Edinburgh as a research site as a means of answering this question. Brette and Bath both saw the potential within Edinburgh's antenatal population, for gleaning information on heterosexual transmission of the disease. Brette, at this point, favoured anonymous screening.

The Chief Medical Officer (CMO) of the SHHD, Ian MacDonald, also considered Edinburgh, as well as Dundee, as a suitable site for research and, by early 1987, he had held two meetings with obstetricians, Chief Administrative Medical Officers (CAMOs) and Community Medicine Specialists (CMSs) from Dundee and Edinburgh.¹²⁵ One such meeting proposed that the research screening programme should be on a named, as opposed to an anonymous basis. Obstetricians in Edinburgh

¹²³ Scottish Home and Health Department, *Report of the National Working Party on Health Service Implications of HIV Infection* (Edinburgh, May 1987), p. 36.

¹²⁴ *Ibid*, p. 5.

¹²⁵ LHSA, EUL, GD24, C5, D4 (3) 2.5.0/2.5.1 – Chief Scientists Ad Hoc Working Party on Research Report of HIV Infection and AIDS – General and Minutes - Minutes of Fourth Meeting, 7 April 1987.

and Dundee were initially against the idea, but were later convinced.¹²⁶ With the recommendation now endorsed in the Tayler Report, Forsyth announced to the House of Commons that all pregnant women in Edinburgh and Dundee would be urged to have AIDS tests in a bid to discover how far the virus had spread.¹²⁷

Some newspapers responded with an announcement that ‘pregnant women in two Scottish cities were yesterday urged to take AIDS tests because of the high level of heroin addiction’.¹²⁸ It went on to say that the two cities [Edinburgh and Dundee] had become ‘the worst AIDS blackspots in Britain’.¹²⁹ The *Edinburgh Evenings News* reported the views of the Catholic Church in Scotland, which was one of condemnation. Father Tom Connelly, Press Officer for the Roman Catholic Church in Scotland claimed that the Government were encouraging abortions by saying that “[I]f your child is infected, we will destroy it”.¹³⁰

A similar response was also forthcoming from the Scottish Branch of the Society for the Protection of Unborn Children.¹³¹ The SHHD’s view was that any decisions over the need for an abortion were a matter for individual women and their medical advisers.¹³² The SHHD had drafted replies to both these organisations on behalf of Forsyth, outlining that the Government had no clear policy on abortion. The letters were never sent since, as these were the only two complaints, it was felt to be best to

¹²⁶ *Ibid.*

¹²⁷ ‘Hospitals set for AIDS Battle Units’, *Scottish Daily Record*, 17 July 1987.

¹²⁸ ‘AIDS call to Mums’, *The Scottish Sun*, 17 July 1987.

¹²⁹ *Ibid.*

¹³⁰ ‘Mums-To-Be Test Plan Under Fire’, *Edinburgh Evening News*, 17 July 1987.

¹³¹ NAS, SOE12/524, Letter, M. Forsyth to R. Reddy, Scottish Development Office, Society for the Protection of Unborn Children, 4 August 1987.

¹³² *Ibid.* Minute, M. Lugton to M. Forsyth, 23 July 1987.

keep the issue quiet and not 'reopen the matter by means of Ministerial correspondence at this stage'.¹³³

Subsequently, research proposals were submitted by the Tayside and Lothian Health Boards to the SHHD, which had received prior encouragement and support from the Medical Research Council (the MRC provided the funding) and the Royal College of Obstetricians and Gynaecologists (RCOG).¹³⁴ The research was to carry out a three-year study on a voluntary named basis in the two cities of Dundee and Edinburgh.¹³⁵ This would involve around 40,000 women. Those screened would be assessed as falling into either low-risk or high-risk categories, with those in the latter category offered counselling prior to a test, if appropriate. Those who did not want to participate would be asked to take part anonymously. Fearing further controversy over the issue, the Scottish Office decided against a public announcement on the commencement of the research, which started in Edinburgh in December 1988. Instead, they wrote directly to Health Boards with copies of letters to be sent to all GPs.¹³⁶

The screening programme remained contentious and created tensions between medics and non-medics, particularly over ethical issues. For example, the Secretary of a Clinical Staff Committee at the City's Eastern General Hospital wrote to the LHB expressing concern about the method of the study. The Committee felt that in such a sensitive subject, face-to-face communication, informing each woman of the research,

¹³³ *Ibid.*

¹³⁴ NAS, HH61/1305, Minute, R. Scott to Mr Stevenson, 15 October 1987.

¹³⁵ LHSA, EUL, GD24, C5, D4 (3) 2.5.0/2.5.1 – Chief Scientists Ad Hoc Working Party on Research Report of HIV Infection and AIDS – General and Minutes - Minutes of Fifth Meeting, 30 September 1987.

¹³⁶ *Ibid.* C6, D2, (13.1.0) – Ante-Natal Screening Project (Part 2) – Minutes of Steering Group on Antenatal Screening for HIV Infection, 24 November 1988.

would have been more appropriate than a letter enclosed with a booking appointment before they arrived at the hospital.¹³⁷ Furthermore, concern was also expressed that the letter failed to emphasise that the research was being done on a voluntary basis, giving the impression that women had little choice in the matter. An additional criticism was that the letters of invitation to take part in the research had been sent out on Eastern General Hospital notepaper, thus implying that the study was only being carried out there and not at any of the other maternity hospitals in Lothian. The Committee felt strongly that the latter would dissuade some patients from booking at that clinic.¹³⁸ It was also noted that some Edinburgh GPs were reluctant to accept the assurance of the Association of British Insurers that their patients would not be penalised by participating in the study.¹³⁹ Other doctors simply advised their patients not to take part in the project.¹⁴⁰

The screening study also generated complaints outwith the medical profession, particularly from women's groups or individual women. These complaints focussed around concerns over the study's counselling services and the means of informing women about test outcomes.¹⁴¹ One voluntary group wrote to the LHB on behalf of a client who had complained that she was told that she could not receive her requested termination until her HIV test result was known.¹⁴² It was felt that this decision had been reached with the safety of clinical staff in mind, purely on the basis that the woman was a drug user and came from one of Edinburgh's deprived areas, where HIV was prevalent, even though she had never injected drugs. The LHB response put

¹³⁷ *Ibid* – Letter, G. A. Venters to W. J. Tayler, LHB, n.d.

¹³⁸ *Ibid.*

¹³⁹ *Ibid*, Minutes of Steering Group on Ante-Natal Screening for HIV Infection, 17 January 1989.

¹⁴⁰ *Ibid.*

¹⁴¹ *Ibid*, Letter, T. Sellers, Women and HIV/AIDS Network, to J.B. Scrimgeour, 28 June 1990.

¹⁴² *Ibid*, Letter, N. Stewart, Castle Project, to Whom It May Concern, LHB, 24 August 1990.

the incident down to a failure of communication rather than one of discrimination.¹⁴³

A similar complaint from a patient, which was published in the local press, was thought to have contributed to a rapid increase in the test refusal rate during the second quarter of the study.¹⁴⁴

The introduction of screening of all antenatal patients in Edinburgh highlights the changing perception of HIV/AIDS, from that of a disease associated with men to one that came to be increasingly associated with women, such that by the second half of the 1980s women came to be viewed as the 'reservoirs of infection'. Data from Edinburgh (along with Dundee) were used to inform debates over the need to adopt a Scottish policy of screening for women. For women in these cities, this pilot study may have proved difficult as they were faced with the decision as to whether or not to have the test in addition to all else. Finally, attention to screening measures for HIV in pregnant women revealed that the medical response to this disease was far from homogenous, even within a particular medical speciality such as obstetrics and gynaecology, where differences of opinion existed over ethical concerns about the screening process.

On a UK level, debates over screening continued throughout this period. A Working Group on Monitoring and Surveillance of HIV infection and AIDS had been created by the DHSS in 1987 and was chaired by Dr Joe Smith.¹⁴⁵ The Report favoured voluntary testing on a named basis, especially of antenatal patients as a means of measuring the extent of heterosexual spread. Pilot studies had commenced in three

¹⁴³ *Ibid*, Letter, G. Bath to N. Stewart, 19 September 1990.

¹⁴⁴ *Ibid*, Minutes of Edinburgh Executive Committee on Antenatal Screening for HIV Infection, 8 August 1989.

¹⁴⁵ Department of Health and Social Security, *Report of Working-Group on the Monitoring and Surveillance of HIV Infection and AIDS* (London, 1988).

UK clinics by the spring of 1988.¹⁴⁶ The Report was not in favour of anonymous testing but acknowledged that it should be considered if testing on a voluntary, named basis proved difficult.¹⁴⁷

The view in the SHHD was that anonymous testing was of limited application, especially in areas such as Edinburgh where the presence of HIV had already been identified and the main concern was its distribution amongst certain social groups.¹⁴⁸ However, by late 1988, the UK Government approved anonymous testing. Berridge argues that the move towards anonymous screening came not from a change in medical opinion but from a change of political heart by the then Secretary of State, Kenneth Clarke, who favoured it.¹⁴⁹

This chapter has suggested that the policy response to AIDS in Edinburgh after the publication of the Tayler Report produced a strong relationship between local factors and national policy decisions, especially within the context of Scotland. The Tayler Report drew much of its evidence from Edinburgh's experience and initiatives with respect to the care and treatment of AIDS sufferers and the antenatal screening of women. However, while local factors are seen to have shaped national policy, this chapter has also shown that once local issues become national concerns, such as the establishment of the Special AIDS Unit, this can result in the delay of the end product, at a local level, not least because of financial issues.

¹⁴⁶ Berridge, *AIDS in the UK*, p. 211.

¹⁴⁷ NAS, SOE12/520, Minute, C. M. A. Lugton to M. Forsyth, 11 November 1988.

¹⁴⁸ *Ibid.*

¹⁴⁹ Berridge, *AIDS in the UK*, p. 211.

CHAPTER 8 - 'TAKE CARE' - 1987-1989

This chapter explores the policy response to AIDS in Edinburgh from mid 1987 to 1989, with respect to the controversial issues of drug misuse and health education policy. While this reveals a general shift towards a more liberal policy response, prompted in part by criticisms from national bodies and fears of a heterosexual epidemic, ongoing debates remained over needle exchange and methadone prescription. This was particularly so within the local medical profession. An examination of developments in the area of needle exchange and methadone provision shows the efforts of Scottish Home and Health Department (SHHD) to encourage both General Practitioners (GPs) and psychiatrists to become more involved in the management of drug misuse. The final section of this chapter focuses on developments within health education, illustrating differences in approaches between Scotland and the rest of the UK. It also pays particular attention to the launch of Edinburgh's own 'Take Care' health education campaign, which reflected local concerns over the potential for heterosexual spread of AIDS.

Needle Exchange Schemes in Scotland

At the end of the summer of 1987, the SHHD began to reassess the three needle exchange schemes in Scotland. It was thought, particularly in the case of the Dundee and Glasgow schemes, that take up had been poorer than expected and fraught with difficulties. Dundee, which offered needle exchange in three different sites and was open for longer hours than the other two centres, wound down in September 1987, having encountered opposition from the medical profession and other health service

staff, within one of the exchange centres.¹ Glasgow had needed to rethink its initial location, because of local opposition and had finally opened in June 1987. However, local resistance was also encountered at the new location, necessitating police presence outside the scheme during the first few weeks of its operation. This scheme operated for three hours per day, Monday to Thursday.² The Edinburgh scheme, where the exchange only opened one afternoon a week, was considered to have been more successful. More than 80 clients had used the service and 10-20 of these had been seen each week. Staff working at the exchange considered it to be a success and felt it should be extended beyond Leith to drug misusers elsewhere in Edinburgh, who continued to share equipment.³ In addition, there had been no opposition to the Scheme by the general public.⁴

The monitoring and assessment work, which was carried out centrally on behalf of the Department of Health and Social Security (DHSS), pointed to additional problems with the Scottish schemes.⁵ In Dundee, the Wishart Drug Problems Centre had not received funding for staff and had been told to start without this support. The GUM clinic in Dundee was under-staffed and there had been difficulties in trying to track down the one GP who was offering exchange facilities. In Edinburgh, it was commented that the limited number of syringes (three) available, along with limited opening hours was insufficient to address patients needs or reduce risk.⁶ The researchers also highlighted the fact that the SHHD had funded the schemes for a

¹ National Archives of Scotland [NAS], HH61/1246, Minute, C. M. A. Lugton to M. Forsyth, 24 September 1987.

² *Ibid.*

³ *Ibid.*

⁴ *Ibid.*, Minute, A. Morrison to W. McKay, 13 July 1987.

⁵ *Ibid.*, Letter, A. Kauder, DHSS to C. Lugton, SHHD, 4 August 1987

⁶ *Ibid.*

period of six months, while the rest of the UK centres were being funded for a year, a period felt to be more appropriate for assessment and monitoring purposes.⁷

In addition, the researchers' fieldwork raised concerns over Scottish HIV-positive injecting drug misusers travelling to London to work in prostitution and to attend clinics for methadone. Their report also stated that there was complacency, confusion and ignorance about the risks of HIV, particularly with respect to its sexual transmission. In addition, high levels of needle sharing by clients who were enrolled in schemes continued to take place.⁸

These observations generated much discussion between the SHHD and the Health Minister, Michael Forsyth.⁹ Various suggestions were put forward by the SHHD, ranging from opting out of the schemes at the end of the six month period to attempting to get more GPs and/or pharmacists involved in the provision of needles and syringes. Reluctantly, it was considered that, given the uncertain start the schemes had experienced, a further six months of funding should be made available to the two schemes still operating.¹⁰ Thus, by October 1987, George Bath was able to report to the Regional AIDS Group (RAG) at the Lothian Regional Council (LRC) that the Leith needle exchange scheme had been extended for a further 6 months and that proposals were being put forward to provide additional time in Leith and to provide another exchange in the City.¹¹

⁷ *Ibid.*

⁸ *Ibid.*

⁹ *Ibid.*, Minute, C. M. A. Lugton to M. Forsyth, 24 September 1987.

¹⁰ *Ibid.*

¹¹ LHSA [Lothian Health Services Archive], EUL [Edinburgh University Library], GD24, C5, D2, (2.2.1), Regional AIDS Group – Agenda and Minutes (Part 1), Minutes of RAG, 13 October 1987.

While the SHHD retained serious misgivings, other groups in Scottish society were more accepting of the schemes as a sensible strategy for the control and spread of HIV. For example, in a letter to the Secretary of State for Scotland, the General Secretary of the Congregational Union of Scotland informed him that, at a recent meeting of the Church Leaders' Forum, there was a 'unanimous view that free needles for drug users should be made available as soon as possible in Scotland'.¹²

By late 1987, the Scottish branch of the British Medical Association (BMA) was also beginning to modify its views on the role of General Practitioners (GPs) in treating drug misuse. In an article in the *Health Service Journal*, the Scottish Secretary of the BMA claimed that the SHHD and Ministers had placed too much emphasis on making abusers give up drugs rather than promoting safe injection. As a consequence of this lack of flexibility the BMA claimed that the Scottish Office were preventing doctors from gaining access to drug misusers.¹³ The statement appeared to surprise the new Health Minister, Michael Forsyth. In a Scottish Office News Release he said:

I have noted with astonishment, that the Scottish Secretary of the BMA has expressed concern about the approach of the SHHD to the problem of AIDS and drug misuse in Scotland, and has suggested that the BMA had difficulty in persuading the Department to promote any needle exchange schemes in Scotland ... These schemes have had to be predominantly based in hospital clinics rather than being run by GPs because it was indicated to us in subsequent discussions with the profession that there was reluctance on the part of many GPs to become involved in needle exchange.¹⁴

¹² NAS, HH61/1310, Letter, R. Waters, General Secretary, Congregational Union of Scotland to M. Rifkind, 11 September 1987.

¹³ 'Call to Change Attitude on Drugs', *The Health Services Journal*, 22 October 1987, p. 1212.

¹⁴ NAS, HH61/1305, Scottish Office News Release, 22 October 1987.

However, Forsyth welcomed the change in attitude and offered to clarify his intentions with respect to AIDS at a BMA conference on General Practice and HIV Infection in Scotland, scheduled for early November 1987.

At the conference GPs were told that, if needle exchange and counselling facilities were to be considered, he would hope to be able to secure their support and co-operation.¹⁵ The Minister also declared that the Government attached great importance to the role of the GP in tackling this major public health problem. The following day it was reported that, at the end of the BMA Conference, 100 delegates took part in a straw poll, which showed that there was a 50-50 split over the question of GPs' willingness to take part in the provision of clean needles to drug misusers.¹⁶

In 1988, a report by the Advisory Council on the Misuse of Drugs (ACMD) was highly critical of the pilot syringe schemes in Scotland and noted that they were very different from the schemes in England. They were hospital based, medically supervised, had restricted opening hours and only supplied three syringes per visit and thus were not very 'user friendly'.¹⁷ By contrast in England, schemes were run by voluntary and NHS drug agencies, had longer opening hours and a greater number of syringes supplied per visit.¹⁸ The Report recommended measures needed specifically in Scotland, stating that 'all injecting drug misusers must have easy, uncomplicated

¹⁵ *Ibid*, Speech Notes for Mr Forsyth – BMA Conference – General Practice and HIV Infection in Scotland – 4 November 1987.

¹⁶ C. Reekie, 'GPs Urged to Help Needle Schemes in Fight Against AIDS', *The Glasgow Herald*, 5 November 1987.

¹⁷ Department of Health and Social Security, *AIDS and Drug Misuse – Part 1 – Report by the Advisory Council on the Misuse of Drugs*, (London, Her Majesty's Stationery Office, 1988), p.57.

¹⁸ R. Lart, 'HIV and English Drugs Policy', Unpublished Ph.D. Thesis (University of London), 1996, p. 94.

access to advice on safer practices and to sterile injecting equipment'.¹⁹ Community-based services, that were accessible in terms of location and opening hours to suit the habits of drug misusers, would be required. In addition, access to syringes and needles through community pharmacies would be needed. Evidence had been given to the ACMD from a number of Edinburgh medical personnel, including advocates of harm minimisation such as Bath, Brett, Robertson and Dr Judy Greenwood, a consultant psychiatrist who had medical responsibility for the Edinburgh needle exchange.²⁰

The response from the Scottish Office was that the ACMD's description of the position in Scotland had failed to give an entirely balanced assessment of the situation.²¹ However, Forsyth told the House of Commons that he would take the recommendations into account when considering what further action might be appropriate for the Government to take.²²

Following the ACMD Report, the SHHD continued to encourage GPs to become involved in the management of drug misuse. In 1988, the Scottish National Medical Consultative Committee created a Working Group to assess the medical role in the prevention and management of drug abuse. The subsequent Report emphasised the importance of the medical role in relation to HIV infection in drug misusers, including

¹⁹ Department of Health and Social Security, *AIDS and Drug Misuse – Part 1 – Report by the Advisory Council on the Misuse of Drugs*, (London, Her Majesty's Stationery Office, 1988), p. 58.

²⁰ Copies of written evidence from Edinburgh medical staff can be found in NAS, HH61/1197.

²¹ NAS, SOE12/517, 'Drug Misuse and AIDS', 29 March 1988.

²² *Ibid*, 'Scottish Office News Release – Mr Forsyth Comments on Government Response to AIDS and Drugs Problems', May 1988.

the role of GPs and psychiatrists and recommended that its findings should be widely circulated throughout the medical profession.²³

Edinburgh Needle Exchange

In reaction to the ACMD's concerns, further developments in the provision of needle exchange in Edinburgh had taken place, rendering provision somewhat more liberal than in earlier years. The SHHD had supported the promotion of more needle exchange facilities in Edinburgh.²⁴ The LHB extended the opening hours at the Leith Needle Exchange and also opened a new exchange in another area, Craigmillar, in addition to launching a 'mobile bus' to deliver supplies across the city.²⁵ The SHHD had also approved needle and syringe provision through pharmacies, although individuals were required to pay. In Edinburgh, around 16 pharmacies had indicated a willingness to participate.²⁶ In addition, the SHHD had also cleared the way for GPs to issue injecting equipment and condoms in the context of treatment for drug misuse.²⁷

However, a further survey carried out in 1989 in Edinburgh showed there was still considerable resistance amongst GPs to become involved in the management of drug

²³ Scottish Home and Health Department, Scottish Health Service Planning Council, *The Medical Role in the Prevention and Management of Drug Abuse – Report of a Working Group of the National Medical Consultative Committee* (SHHD, May 1988), pp. 1- 6.

²⁴ NAS SOE12/253, Minute C. M. A. Lugton to Smith, 10 February 1989.

²⁵ LHSA, EUL, GD24, B19, HIV/AIDS Back Up Services Resource Folder, Document, Lothian Health Board, *AIDS in Lothian – Time to Take Care - Report in Response to AIDS (Control) Act 1987* (LHB Year Ending 31 March 1989), p. 12.

²⁶ NAS, SOE12/253, Minute, C. M. A. Lugton to Smith, 10 February 1989.

²⁷ *Ibid.*

addiction.²⁸ Clearly, Edinburgh and Scotland were not unique in their reluctance. As others have shown, despite concerns about HIV/AIDS, GPs throughout the UK were reluctant to becoming involved.²⁹ Moreover, as will be shown in the context of the debate over methadone therapy, this reluctance was also shared by psychiatrists.

Methadone Prescription

By the end of 1987, the policy on the prescription of opiate substitute drugs to HIV-positive individuals in Edinburgh had come under severe criticism. The Scottish Drugs Forum (a co-ordinating agency for those concerned with drug problems in Scotland) stated that the prescription of opiate substitution should not depend solely on the sero-positivity of the client.³⁰ The ACMD Report on Scotland stated that the practice of prescribing methadone to only those patients who were HIV-positive was absurd and 'its use to prevent sero-negative drug misusers from engaging in HIV risk behaviour and acquiring the virus [was] virtually non-existent'.³¹ The ACMD also noted that the lack of psychiatric input in Scotland in the role of management of drug misuse contributed to the unwillingness of many GPs to provide care for drug misusers without specialist (back up) support.³² The ACMD recommended that psychiatric input to the management and treatment of drug misuse was urgently

²⁸ A. M. Richardson and P. A. Gaskell, 'HIV Infection and AIDS in Lothian', in M. Pye, M. Kapila, G. Buckley and D. Cunningham (eds), *Responding to the AIDS Challenge - A Comparative Study of Local AIDS Programmes in the United Kingdom* (Essex, Longman Group, 1989), p. 83.

²⁹ S. G. Mars, 'Prescribing and Proscribing: The Public-Private Relationship in the Treatment of Drug Addiction in England, 1970-1999', Unpublished Ph.D Thesis (London School of Hygiene and Tropical Medicine, 2006), p. 48; A. Glanz, 'The Fall and Rise of the General Practitioner' in J. Strang and M. Gossop (eds), *Heroin Addiction and Drug Policy - The British System* (Oxford, Oxford University Press, 1994), pp. 151-66.

³⁰ NAS, HH61/1198, 'Scottish Drugs Forum - Policy Statement on AIDS', September 1987. p. 1.

³¹ Department of Health and Social Security, *AIDS and Drug Misuse - Part 1 - Report by the Advisory Council on the Misuse of Drugs* (London, Her Majesty's Stationery Office, 1988), p. 57.

³² *Ibid*, p. 56.

needed, with full-time posts for consultant psychiatrists specialising in drug misuse needed for Glasgow and Edinburgh. Furthermore, the report recommended that the value of substitute prescribing required to be recognised.³³

In an effort to address these issues, the SHHD arranged a meeting with the Scottish Division of the Royal College of Psychiatrists (RCPsych) to establish their views on the matter.³⁴ It was clear from this meeting that the issue of prescribing maintenance methadone was still highly controversial amongst Scottish psychiatrists. Historically, in the 1960s, as discussed in Chapter 2, Edinburgh doctors had been unenthusiastic about the medicalisation of drug misuse (as drug dependence) and unconvinced of the value of maintenance methadone treatment in an often reluctant and thankless patient group, who did not consider themselves mentally unwell. In 1987 these concerns had not diminished nor changed in nature. Psychiatrists remained of the view that many service users would regard methadone as no more than a substitute drug and some would be at risk of including methadone within a pattern of poly-drug use, which would therefore be sustained.³⁵ Other patients would sell their treatment on the black market. The meeting was also informed that many psychiatrists did not have experience in dealing with drug misusers and it was therefore diffidence rather than unwillingness that prevented them from accepting a role in the management of drug misuse.³⁶

The Chief Medical Officer (CMO) of the SHHD, Ian MacDonald, concluded from the meeting that further clarification of the input, which the psychiatric service could

³³ *Ibid*, p. 78.

³⁴ NAS, HH61/1446, 'Minute of Meeting with Representatives from the Scottish Division of the Royal College of Psychiatrists', 28 April 1988.

³⁵ *Ibid*.

³⁶ *Ibid*.

make to the treatment and management of drug misuse was needed from the profession itself and from other relevant medical professions, such as GPs and Community Medicine Specialists (CMSs). One RCP representative at the meeting, Dr Boyd, undertook to circulate a paper for discussion at the RCP's summer meeting to establish the views of its psychiatric members and report back.³⁷

The Creation of the Community Drug Problem Service

Another RCP representative at the meeting was Judy Greenwood. Greenwood was one of the few psychiatrists at the meeting to argue that the existence of HIV infection called for a user-friendly approach which offered a wide range of services for the management of drug misuse. She explained that she had just set up an experimental Community Drug Problem Service (CDPS) in Edinburgh, which was based on a multi-disciplinary model (as recommended in the ACMD Report), which included a few GPs who were willing to prescribe methadone. She herself acted as the co-ordinator for (back-up) services.³⁸

Other staff included community psychiatric nurses, a medical secretary, voluntary drug agency workers and social workers. This new service was a specialist referral service (essentially from GPs) available to all drug misusers, regardless of their HIV status. It adopted a 'harm minimisation' approach for continuing drug misusers in order to prevent the further spread of HIV.³⁹ Greenwood said that a number of

³⁷ *Ibid.*

³⁸ *Ibid.* See also, Department of Health and Social Security, *AIDS and Drug Misuse – Part 1 – Report by the Advisory Council on the Misuse of Drugs* (London, Her Majesty's Stationery Office, 1988), pp. 28-9.

³⁹ NAS, HH61/1446, 'Minute of Meeting with Representatives from the Scottish Division of the Royal College of Psychiatrists', 28 April 1988.

safeguards had been put in place such as the cessation of prescriptions if drug misusers used other drugs and if methadone was being traded.⁴⁰ GPs had been sent an explanatory letter informing them of the service and requesting their help to curb the spread of HIV.⁴¹ GPs were encouraged to prescribe methadone and offer physical health care to their drug-misusing patients.⁴²

Greenwood had long been an advocate of a community-based approach to drug misuse management. She had been working in North West Edinburgh, where there was a high incidence of drug-taking and HIV positivity, especially in the Pilton/Muirhouse areas. A number of drug workers in this area were part of the Edinburgh Drug Abuse Action Group (EDAAG), which consisted of professional and voluntary workers who gathered information and shared knowledge about the increasing drug misuse in Edinburgh. This group, as mentioned in Chapter 2, was in favour of community-based approaches.

In early 1986, Greenwood wrote to the SHHD with an outline proposal, along similar lines to the CDPS, to deal with the health care and social support of those ill or dying from AIDS in North West Edinburgh.⁴³ However, the proposal was shelved by the LHB in the light of imminent changes within the psychiatric sector in the North West Edinburgh area.⁴⁴ At the end of 1987, Greenwood and Bath began work on a new proposal to develop the CDPS to cover all of Edinburgh. By 1988, her proposal was accepted and supported without hesitation by the LHB, reflecting a change of heart in

⁴⁰ *Ibid.*

⁴¹ J. Greenwood, 'Shared Care with General Practitioners for Edinburgh Drug Users', Paper Presented at the VIth International Conference on the Reduction of Drug Related Harm, Florence, March 1995. For a full copy see www.drugtext.org/library/articles/96716.html.

⁴² *Ibid.*

⁴³ LHASA, LHB37/164, 'A Strategy for Management of AIDS in Lothian', Appendix 4, December 1986.

⁴⁴ *Ibid.*

the commitment of LHB and SHHD to the support of drug services, arguably in the light of the ACMD Report. Greenwood's post was also converted from a part-time community psychiatrist post to a full-time consultant post, devoted to the CDPS funded by money that had been earmarked for AIDS from the SHHD.⁴⁵ Indeed, the Scottish Office announced in September 1988 that an extra £300,000 was to be made available to expand and improve services for drug misusers.⁴⁶

Continuing Psychiatric Reluctance

While the CDPS was being established in Edinburgh, the SHHD continued to explore ways in which to encourage psychiatrists in Scotland to become more involved in the management of drug misuse. The Working Group of the National Medical Consultative Committee also reported that very few psychiatrists in Scotland continued to prescribe methadone following acute detoxification of a heroin misuser.⁴⁷ Furthermore, the Report noted that psychiatrists would accept responsibility for the treatment of mental illness of drug misusers and supervision of detoxification regimes but preferred the subsequent management of drug misusers to be in the setting of a multidisciplinary team, where they may or may not take a leading role. Community-based programmes with psychiatric input were favoured over hospital-based programmes.⁴⁸

⁴⁵ J. Greenwood, 'Creating a New Drug Service in Edinburgh', *British Medical Journal*, 300 (1990), p. 587.

⁴⁶ NAS, SOE12/520, Scottish Office News Release, 'Initiatives on Drug Misuse and the Role of the NHS', 30 September 1988.

⁴⁷ SHHD, Scottish Health Service Planning Council, *The Medical Role in the Prevention and Management of Drug Abuse – Report of a Working Group of the National Medical Consultative Committee*, (SHHD, May 1988), p. 12.

⁴⁸ *Ibid.*.

This Report was followed by Boyd's feedback from RCP members at their summer meeting. Boyd also confirmed to the SHHD that there was a general consensus amongst psychiatrists in Scotland that their role in dealing with the problem of drug misuse was very limited and that many were still reluctant to use substitute drugs on a maintenance basis. He went on to stress that some of his colleagues had devoted a great deal of energy and professional time in this area of work but that they were convinced that not all drug misusers needed psychiatric treatment, and that, just because some were 'disruptive in the general practitioner's surgery, or create[d] trouble in a medical ward, or behave[d] in a socially unacceptable way [did] not necessarily make it appropriate that, they should be treated by a psychiatrist'.⁴⁹ Boyd concluded that despite these reservations, the Scottish Division of the RCP would give their full support and encouragement to psychiatrists involved in community-based drug misuse projects as recommended by the ACMD.

MacDonald was disappointed in the attitude of psychiatrists as relayed by Boyd. This left him in a quandary about what to do next. He subsequently invited representatives from psychiatry and other specialties involved with drug misuse to take part in a wider meeting at the SHHD to discuss the complex issue of treatment for drug misusers.

It would appear from that meeting, which was held in late 1988, that little had changed in the minds of psychiatrists as to their role in the treatment of drug misuse. MacDonald stated that the principal issue arising from the meeting was the continued objection of many psychiatrists to the use of substitute prescribing, even as a means of

⁴⁹ NAS, HH61/1446, Letter, W. D. Boyd to I. MacDonald, 12 July 1988.

preventing the spread of HIV infection.⁵⁰ The two main grounds for psychiatrists' objections were the danger of an increase in the number of youngsters who might take up the misuse of drugs by injection, should drugs become freely prescribed, and the danger that imported heroin would be diverted from misusers on substitute drugs to new participants.⁵¹ MacDonald concluded that 'the thesis that HIV is a greater threat to society than drug misuse does not appear to be accepted by our psychiatric colleagues'.⁵²

In Edinburgh, similar views were expressed. Writing to the Chief Administrative Medical Officer (CAMO), the Chairman of the Area Division of Psychiatry in Lothian stated that, although some medical practitioners were prescribing maintenance methadone as a means of preventing the spread of HIV, it had gone 'out of fashion' in Edinburgh psychiatric circles, because there was evidence that it increased the amount of opiate substitute in circulation in the community.⁵³ However, he stated that his members were fully supportive of the type of community-based multi-disciplinary programme devised by Greenwood because it was the view of hospital staff, and of addicts themselves that 'a psychiatric hospital is a bad place' for the treatment of drug misuse.⁵⁴

Greenwood appears to have been only one of a few psychiatrists in Edinburgh who were prepared to prescribe or support treatment with methadone on a maintenance basis. She claims that her approach to drug misuse was seen as 'soft' by most of her

⁵⁰ *Ibid*, 'The Psychiatrist's Role in AIDS and Drug Misuse' – Meeting held in St Andrew's House on 14 October 1988.

⁵¹ *Ibid*.

⁵² *Ibid*.

⁵³ LHSA, EUL, GD24, C6, D1 (9.4.0), 'CDPS – 3 February 1989– June 1992', Letter, A. K. Zealley to H. Zealley, 24 January 1989.

⁵⁴ *Ibid*.

colleagues.⁵⁵ She said that ‘they thought if they gave me enough rope I would hang myself. Drug problems were an anathema to them. I’m not exaggerating. There was a lot of antipathy. It was ‘we don’t want them in our corridors’ and all that was on offer was three weeks if you wanted to come off [drugs] – if you don’t – go away... But I was too old to be brainwashed by them’.⁵⁶

Thus, it was up to Greenwood and others involved in the CDPS to encourage GPs to take on a more active role in the management of drug misuse and especially to prescribe methadone. Greenwood found this task equally arduous, as many GPs shared the same reluctance as psychiatrists. A survey carried out shortly after the CDPS opened in 1988 indicated that a total of 47% would not prescribe methadone.⁵⁷ One reluctant GP criticised the LHB for making it easy for drug addicts to obtain supplies of the drugs they desired and that the policy of prescribing methadone was nothing more than a ‘junkies charter’.⁵⁸

Greenwood claimed that her first two years working in the CDPS was the most stressful experience of her professional career, because of ‘opposition from the psychiatrists [and] hostile GPs’.⁵⁹ However, she continued to encourage GPs to prescribe methadone and argued that ‘embarking ...on an unproved but commonsense reduction approach of controlled substitution treatment with methadone and providing equipment and condoms would indicate a responsible attempt to maintain contact with drug users, try to alter their behaviour, and hopefully curb the spread of the

⁵⁵ *Ibid.*, GD25, B6, Document, ‘Draft Outline: Confidential’, 12 August 1996. This is a 41-page draft proposal for a paper/book on the HIV epidemic in Edinburgh based on interviews with key players in Edinburgh, which included Judy Greenwood.

⁵⁶ *Ibid.*

⁵⁷ Greenwood, ‘Shared Care with General Practitioners for Edinburgh Drug Users’.

⁵⁸ I. McKee, ‘A Junkies Charter’, *Edinburgh Medicine*, 58 (1989), p. 3.

⁵⁹ *Ibid.*

potentially fatal HIV virus'.⁶⁰ Her efforts appear to have proved fruitful for, in 1989, the CDPS's model of shared care was given as an example by the ACMD as an effective model of care for drug misusers, whose health 'considerably improved and risky behaviour reduced'.⁶¹ The ACMD recommended that shared care approaches should be adopted so that GPs and physicians combine to treat drug misuse.⁶²

The development of the CDPS in relation to the response to HIV/AIDS has revealed several factors, which determined this type of policy. Firstly, the extent to which Edinburgh psychiatrists were prepared to treat drug misuse with substitute therapies played an important role in the establishment of the CDPS. Their reluctance to prescribe methadone stemmed from concerns that this type of treatment was ineffective in reducing drug misuse and may even have been responsible for encouraging individuals to develop this type of behaviour. Psychiatrists were also of the view that the treatment of drug misuse was not solely a psychiatric responsibility and consequently saw their role as limited. Secondly, the reluctance to prescribe methadone maintenance therapy continued a long history of resistance within Edinburgh psychiatry to the prescription of heroin or methadone on a maintenance basis. The main form of treatment from the establishment of the Royal Edinburgh Hospital as a Drug Treatment Centre in 1968 was detoxification.⁶³ Even by the 1970s, only one psychiatrist attempted maintenance therapy but this was short-lived. However, as others have shown, there was disillusionment amongst psychiatrists not only in Scotland but elsewhere in the UK by the late 1970s. Because methadone prescription did not really result in a cure for opiate dependence, efforts were

⁶⁰ Greenwood, 'Creating a New Drug Service in Edinburgh', p. 589.

⁶¹ Department of Health, *AIDS and Drug Misuse – Part 2 – Report by the Advisory Council on the Misuse of Drugs*, (London, Her Majesty's Stationery Office, 1989), p. 31.

⁶² *Ibid*, p. 32.

⁶³ See Chapter 2 for more details.

perceived as fruitless in the absence of 'harm minimisation' as a clinical goal. The lack of faith in maintenance therapy and financial cutbacks in drug services were seen as contributory factors to this disillusionment.⁶⁴

Health Education

The Role of The Scottish Health Education Group (SHEG)

As noted in Chapter 6, by 1987, the SHEG had become more active in AIDS education. However, its role in AIDS and drugs education had become increasingly under threat and this revealed wider ideological differences between Scotland and the Department of Health and Social Security (DHSS) over the content of health education programmes. In the summer of 1987, the DHSS began to develop anti-drugs and anti-injecting AIDS mass media campaigns. The newly reconstituted Health Education Authority (HEA)'s remit was to cover mass media AIDS campaigns but this did not happen until the Autumn of 1987.⁶⁵ The DHSS campaigns were based on 'shock-horror' methods of delivery in order to scare people into following the advice on offer. For example, one television commercial, 'Why Me', depicted a young man attending a hospital and being told that he had been found to be HIV-positive.⁶⁶ This was combined with sequences depicting him injecting heroin with dirty equipment into his arm.

⁶⁴ V. Berridge, 'AIDS and British Drug Policy: Continuity or Change?', in V. Berridge and P. Strong (eds), *AIDS and Contemporary History* (Cambridge, Cambridge University Press, 1993), p. 140; S. G. Mars, 'Prescribing and Proscribing: The Public-Private Relationship in the Treatment of Drug Addiction in England, 1970-1999', p. 41.

⁶⁵ V. Berridge, *AIDS in the UK: The Making of Policy, 1981-1994* (Oxford, Oxford University Press, 1996), pp. 194.

⁶⁶ NAS, SOE12/524, Minute, R. Scott to M. Forsyth and the Secretary of State for Scotland, 20 July 1987.

The SHEG had substantial reservations about the anti-injecting material since they believed that the message could be interpreted as suggesting that taking drugs by other routes was more acceptable. SHEG also pointed out that the 'shock horror' approach had never been proven to work except with those least likely to be at risk.⁶⁷ Scotland had traditionally favoured broader health education approaches, which were based on promoting a healthy lifestyle. An example of this was SHEG's anti-drug campaign, 'Choose Life not Drugs' in 1985.⁶⁸ The mass media elements of this campaign emphasised the positive aspects of a drug-free lifestyle and the ability of individuals to make their own decisions. Health educationists, drug workers and also the ACMD, had welcomed this style of campaign. Indeed, the campaign won international praise at a World Conference on Health Education in 1985.⁶⁹

Forsyth was in favour of a UK-wide campaign but was not a strong supporter of 'shock-horror' methods in health education. However, he decided to run the AIDS/anti-injecting campaign in Scotland, because of what he perceived as the severity of the problem - the high incidence of HIV-positive cases related to intravenous drug misuse. The campaign was also seen as cost effective.⁷⁰ He did not sanction the DHSS's anti-drugs campaign, 'Heroin Screws You Up', which was scheduled to run parallel to their AIDS/anti-injecting message. The SHEG approved of this decision and believed Forsyth would sanction their own anti-drug campaign, that was scheduled for release. However, Forsyth felt it was not appropriate to launch

⁶⁷ *Ibid.*

⁶⁸ See Berridge, *AIDS in the UK*, p. 193.

⁶⁹ NAS, SOE12/524, Minute, R. Scott to M. Forsyth and the Secretary of State for Scotland, 20 July 1987.

⁷⁰ *Ibid.*

SHEG's campaign at the same time as the AIDS/anti-injecting message because both campaigns could convey conflicting messages about drug misuse.⁷¹

The decision, to postpone the anti-drug campaign in Scotland, caused apprehension for the SHHD and the SHEG over the latter's role in AIDS and in health education campaigns in Scotland as a whole. An added strain to this concern was the establishment of the new HEA. HEA was directly accountable to Ministers and Parliament and had been given executive responsibility for public education about AIDS. The intention was that the Government would have more control over AIDS education, whilst simultaneously removing its name directly from disagreeable and explicit information.⁷² As stated in Chapter 6, John MacKay, former Health Minister for Scotland was one of the Ministers behind this approach. Berridge has argued that this was part of a 'respectable out' strategy for the Government.⁷³

The DHSS had envisaged that the HEA's task in UK-wide mass media AIDS education would be complemented by health education activities designed to meet local needs and circumstances in which agencies, such as the SHEG, would play a leading role.⁷⁴ This announcement did little to reassure Scottish civil servants, who in principle accepted the idea that mass media AIDS campaigns should continue on a UK-wide basis, but saw these new plans as a threat to their control over health education. The SHHD told Scottish Office Ministers that previous relations with the DHSS on AIDS publicity showed that little priority had been given to Scottish views

⁷¹ *Ibid*, SOE12/522, 'AIDS in Scotland', July 1987.

⁷² NAS, ED48/2203, 'Note for the Record', 9 October 1986.

⁷³ Berridge, *AIDS in the UK*, pp. 191-201.

⁷⁴ NAS, ED48/2203, 'First Draft H(A) [Home Affairs Committee] paper produced by the DHSS on AIDS Public Education Campaign – Transfer of Work to the HEA' – 8 September 1987.

and that the same was likely to be the case with the new HEA.⁷⁵ On a future occasion the SHHD raised their concerns to Forsyth about the launch of a HEA TV campaign, because it failed to include the benefits of cutting down on the number of sexual partners and could stimulate ‘renewed criticism from religious interests in Scotland and to make it more difficult to argue that the campaign as a whole aims to provide a range of practical advice, including that which is consistent with traditional standards of morality’.⁷⁶

Michael Forsyth supported the SHHD and ensured that Scottish views were taken into account at the HEA.⁷⁷ However, Forsyth was generally in favour of HEA work, especially its adoption of a healthy lifestyle approach which complemented the SHEG’s approach.⁷⁸ By early 1989, Forsyth announced the launch of a £200,000 information and education campaign on AIDS and drug misuse, to be carried out by SHEG. The campaign was aimed at 16-25 year olds to raise awareness about the risks of the heterosexual spread of HIV via drug misuse and to enhance young people’s ability to reject drug-taking in any form.⁷⁹

By July 1989 the Scottish Office had decided to review health education in Scotland and examine the way in which it was undertaken at both a national and local level. The review recommended that:

⁷⁵ *Ibid*, HH61/1259, ‘Draft paper by the SHHD to H(A) – Public Education Campaign – Transfer of Work to the Health Education Authority’, 25 September 1987.

⁷⁶ *Ibid*, SOE12/253, Minute, C. M. A. Lugton to M. Forsyth, 7 July 1989.

⁷⁷ *Ibid*, Letter M. Forsyth to J. Moore, 20 April 1989.

⁷⁸ *Ibid*, Minute, C. M. A. Lugton to J. Gilmour, 7 July 1989.

⁷⁹ *Ibid*, SOE12/253, Scottish Office News Release, ‘Mr Forsyth Launches £200,000 Campaign on AIDS and Drug Misuse, 6 March 1989.

a new national health education organisation should be established outside the Common Services Agency but within the NHS, taking its policy guidance direct from the Scottish Home and Health Department.⁸⁰

As discussed in chapters 2 and 4 of this thesis, there had been a long history of the SHHD seeking more control over the SHEG's activities, especially over issues around sex education. By having more control over SHEG, the SHHD, were in a stronger position to have their views fully represented in national health education measures and to include discussions with the DHSS and the HEA. As will be shown, in Chapter 9, the SHEG were replaced by a new health education body in 1991.

Concerns about Heterosexual Spread of HIV in Edinburgh

Meanwhile, local statutory agencies were growing increasingly concerned about the potential risk of heterosexual spread.⁸¹ By March 1988, a total of 842 people had been tested positive for HIV in Lothian, 151 of whom had tested positive in the previous 12 months.⁸² The majority of both male and females patients had become infected through drug misuse and were heterosexual and sexually active. Based on an estimate of the number of people 'at risk' and the probability that they were infected, the LHB AIDS Team calculated that around 1500-2000 people could now be infected Lothian-wide.⁸³ The LHB was worried that failure to prevent the spread by means of public education could have severe economic consequences with respect to patient care and treatment.⁸⁴ With little prospect of a cure or vaccine for AIDS, public

⁸⁰ Scottish Home and Health Department, *Consultation Document – Health Education in Scotland – A National Policy Statement* (SHHD, October 1990), p. 5.

⁸¹ LHASA, EUL, GD24, B19, HIV/AIDS Back Up Services Resource Folder, *AIDS in Lothian – Everyone's Concern - A Report in Response to AIDS (Control) Act 1987* (LHB, March 1988), p. 35.

⁸² *Ibid*, p. 9.

⁸³ *Ibid*, p. 12.

⁸⁴ LHASA, EUL, GD24, B19, HIV/AIDS Back Up Services Resource Folder, Document, *Take Care Campaign Report* (December 1988 – November 1989), p. 2, p. 1.

education was given high priority in the list of services to be provided by the LHB to combat further spread of infection.

The LRC had also expressed increasing anxieties about the potential spread to the heterosexual population via drug abusers whom they classified as ‘largely young, fertile and prone to having multiple sexual partners, either ‘socially’ or for payment in order to sustain their drug habit’.⁸⁵ They aimed to develop a coherent HIV/AIDS education programme and had written to all Lothian schools on this matter, asking them to review their social/health education and sex education programmes.⁸⁶ Responses from a number of schools indicated that further guidance would be welcome and that guidelines on matters relating to sex education and AIDS education were necessary.⁸⁷ Lothian schools were disappointed at the delay in the production of national measures and the lack of financial support from the Scottish Education Department (SED), despite requests.⁸⁸

In addition, local research on heterosexual transmission amongst HIV-positive drug misusers continued to be conducted by Brettle and Robertson, who concluded that an epidemic of ‘heterosexually transmitted AIDS could be about to break out in the City’.⁸⁹ Research work on drug misusers and their regular partners suggested that there were two stages where partners could become infected. The first stage was shortly after the drug misuser had become infected and the second stage, which was

⁸⁵ *Ibid*, C5, D2, (2.2.1), Regional AIDS Group – Agenda and Minutes, (Part 2), Document, Lothian Regional Council – AIDS Support Group – First Progress Report, January, 1988.

⁸⁶ LHSA, EUL, GD22/19/7, ‘The Take Care Campaign’, Letter, Education Department, Lothian Regional Council to all Head Teachers, 25 January 1988.

⁸⁷ *Ibid*.

⁸⁸ *Ibid*, GD24, C5, D2 (2.2.0), Regional AIDS Group – General Part 1, Document, AIDS Support Group – First Progress Report, January 1988, p. 7.

⁸⁹ B. Christie, ‘Fears Grow on Spread of Edinburgh AIDS Menace’, *The Scotsman*, 11 October 1988.

preceded by a long period of non-infectivity, was after they had become clinically ill with AIDS-related conditions.

Compared with the rest of the UK, Lothian's level of HIV infection was over four times the national average.⁹⁰ Berridge has argued that concerns about heterosexual spread, throughout the rest of the UK, had begun to wane by the late 1980s and contributed to the shift in the definition of AIDS from an 'epidemic' to a 'chronic' disease, especially after the publication of the Cox Report in 1988, which revised predictions of HIV infection downwards and changed policy perceptions.⁹¹ Indeed, the belief that a heterosexual epidemic was not looming contributed to arguments that led to the cancellation of an advertising campaign about the use of condoms in the UK.⁹² Furthermore, national media presentations of AIDS in the UK also began to portray heterosexual spread as a myth by suggesting that claims about an epidemic were being used 'as a threat to reassert family values and to deny the young the joys of sexual liberation'.⁹³

The 'Take Care' Campaign

In order to address the potential heterosexual spread of HIV, a city-wide campaign in Lothian known as the 'Take Care' Campaign was launched. This was a joint effort between the LHB and the LRC (with some funding from the SHEG). The LHB

⁹⁰ LHSA, EUL, GD24, B19, HIV/AIDS Back Up Services Resource Folder, Document, *Take Care Campaign Report* (December 1988 – November 1989), p. 2.

⁹¹ Berridge, *AIDS in the UK*, pp. 182-3. See also, Department of Health and Social Security, *Short Term Prediction of HIV Infection in England and Wales - Report of a Working Group*, London, 1988.

⁹² Berridge, *AIDS in the UK*, p. 201.

⁹³ V. Berridge, 'AIDS, The Media and Health Policy', *Health Education Journal*, 50:4 (1991), p. 181.

HIV/AIDS Team's Health Promotion Officer, and the LRC's Education Department were directly involved in developing the campaign.⁹⁴

On the first World AIDS Day, 1 December 1988, a number of public events took place. These included a banner displayed at the top of the Mound overlooking the city centre, with the words 'AIDS Concerns Us All'. Pink cards and car stickers were distributed throughout Edinburgh and the message 'Take Care' was exhibited on all Lothian Regional Transport buses. In addition, the LRC included information on HIV/AIDS in the form of a small 'Take Care' card sent to all of its 50,000 employees. A 'Ready Guide' was also produced which listed all the services and facilities in Lothian for people with HIV and AIDS.⁹⁵

The official launch of the 'Take Care' campaign, which was finally unveiled on Valentine's Day, 1989 in a blaze of publicity, included the driving of a bright pink bus bearing the message 'Take Care of the One You Love' and 'AIDS Concerns Us All' around the city. A press conference, held by George Bath and David Taylor of the LRC, informed the public of the need for a campaign.⁹⁶ Prior to the launch, the SHHD had been concerned that the press conference would be used as an opportunity to criticise them publicly. However, Bath reassured them that this would not be the case and he also agreed to their suggestion that it be indicated that the campaign was being funded by money made available from the Scottish Office.⁹⁷

⁹⁴ LHSA, EUL, GD24, B19, HIV/AIDS Back Up Services Resource Folder, *AIDS in Lothian – Everyone's Concern, - A Report in Response to AIDS (Control) Act 1987*, (Lothian Health Board, March 1988), p. 27.

⁹⁵ LHSA, EUL, GD24, B19, HIV/AIDS Back Up Services Resource Folder, Document, *Take Care Campaign Report* (December 1988 – November 1989), p. 2.

⁹⁶ *Ibid.*

⁹⁷ NAS SOE12/253, Minute, C. M. A. Lugton to M. Forsyth, 10 February 1989.

The ideology informing the 'Take Care' campaign was the promotion of a broad, 'positive' message about love and caring in connection with sex.⁹⁸ The campaign provided information about HIV/AIDS transmission. It warned that the virus could spread when the semen, vaginal fluids or blood of an infected person was transmitted into the blood stream of another person. Advice was given on how to 'Take Care' of yourself and others by choosing not to have a sexual relationship or intercourse, using condoms to reduce the risk should you choose to be sexually active, being faithful to your partner and never sharing needles or syringes.⁹⁹ A decision was made at the outset that the message had to be explicit and direct in order to avoid any confusion.¹⁰⁰

The campaign had four main aims. The first was promotion of the term 'Take Care' and a logo that was easily identifiable to the general public in Lothian. This was achieved using a wide variety of methods which ranged from displaying copies of the logo on the corners of the *Edinburgh Evening News* fortnightly throughout the summer, to the distribution of pink cards bearing the logo throughout arts and entertainment venues in Lothian.¹⁰¹ The local media were evidently reinforcing the 'safe sex' message and being deployed to promote health education. In addition, postcards bearing the 'Take Care of the One You Love' message were delivered to 320,000 homes in Lothian.

⁹⁸ LHSA, EUL, GD24, B19, HIV/AIDS Back Up Services Resource Folder, Document, *Take Care Campaign Report* (December 1988 – November 1989), p. 6.

⁹⁹ *Ibid*, p. 3. See also a wide range of 'Take Care' campaign leaflets in LHSA, GD22, 'The Take Care Campaign'.

¹⁰⁰ LHSA, EUL, GD24, B19, HIV/AIDS Back Up Services Resource Folder, Document *Take Care Campaign Report* (December 1988 – November 1989), p. 3.

¹⁰¹ *Ibid*, p. 8.

The second aim was to link the 'Take Care' theme with information about the ways in which HIV could be contracted. This was done by various means, ranging from articles published in newspapers and staff newsletters, to concerts by local Scottish bands such as Deacon Blue.

A third aim of the campaign was to develop and create an environment in which individuals could practise 'Taking Care'. This was carried out with the help of the Environmental Health Department of the EDC, which promoted the installation of coin operated condom machines in pubs, discos and large workplaces, such as the Health Board and Regional Council departments.¹⁰² Free condoms were also made available through the introduction of a 'C-Card' (condom card) that allowed any adult to collect them at Family Planning Services or the Brook Advisory Centre.¹⁰³ However, given that such centres were traditionally used by women, this suggests that the onus to 'Take Care' was on them, more than men. Condoms were placed inside pill cases, along with packets of prescribed contraceptive pills, and contained information about how to use them.¹⁰⁴ The information also included a question as to whether the reader had decided to prevent sexually transmitted diseases as well as avoiding pregnancy. As some commentators have argued, similar AIDS campaign measures were often based on the assumption that men are 'naturally' less able to exercise self-control when it comes to sex.¹⁰⁵ In addition, little consideration appears to be evident of the wider connotations of women carrying condoms, especially the

¹⁰² *Ibid*, p. 12.

¹⁰³ *Ibid*, p. 13.

¹⁰⁴ This item and several other items including T-shirts, badges, posters can be seen in LHSA, EUL, GD22, - 'The Take Care Campaign'.

¹⁰⁵ This issue is also addressed at the national level by D. Richardson, 'AIDS Education and Women: Sexual and Reproductive Issues', in P. Aggleton, P. Davies and G. Hart (eds) *AIDS – Individual, Cultural and Policy Dimensions* (London, New York and Philadelphia, The Falmer Press, 1990), p. 172.

possibility of a women being seen as 'easy' and willing to have sex, having come prepared.¹⁰⁶

However, when the 'Take Care' campaign material, as a whole, is examined closely, it was often presented in ways that paid little attention to wider gender divisions in society. For example, an emphasis was placed upon the choices of individuals in deciding on whether or how they wished to conduct sexual intercourse. Implicit in this message was that everyone had the same choice. As other commentators on AIDS health education have shown, models that aimed to empower individuals were often limited by social structures such as gender, class, race and age.¹⁰⁷ Indeed, for some women, choice proved difficult in a sexual relationship, where relationships were complex and often far from equal.¹⁰⁸

'Take Care' in Schools

A fourth aim was to support and create educational opportunities for people to explore what 'Taking Care' meant for them.¹⁰⁹ This was targeted specifically at young school leavers, who were seen as one of the most vulnerable groups in society and in especial need of guidance. Several educational resources were provided for young people and their educators. An HIV/AIDS Back-Up Service was created in the LHB's Health

¹⁰⁶ *Ibid.*

¹⁰⁷ H. Homas and P. Aggleton, 'Health Education, HIV Infection and AIDS', in P. Aggleton and H. Homas (eds), *Social Aspects of AIDS* (London, New York and Philadelphia, The Falmer Press, 1988), pp. 154-76.

¹⁰⁸ J. Bury, 'Education and the Prevention of HIV Infection' in J. Bury, V. Morrison, and S. McLachlan (eds), *Working with Women & AIDS* (London and New York, Routledge, 1992), pp. 99-109; D. Richardson, 'AIDS Education and Women: Sexual and Reproductive Issues', in P. Aggleton, P. Davies and G. Hart (eds), *AIDS – Individual, Cultural and Policy Dimensions* (London, New York and Philadelphia, The Falmer Press, 1990), pp. 169-80.

¹⁰⁹ LHSA, EUL, GD24, B19, HIV/AIDS Back Up Services Resource Folder, Document, *Take Care Campaign Report* (December 1988 – November 1989), p. 10.

Education Centre, which provided educators with materials, support and training in HIV/AIDS education. This was supplemented by a monthly newsletter, entitled 'Meridian', which kept people, working in the HIV/AIDS field, abreast of new developments, resources and information.¹¹⁰

Part of the preparation for the materials for schools involved the distribution of a questionnaire to all secondary schools in Lothian, requesting information on the nature of HIV/AIDS education currently being provided.¹¹¹ Feedback from the questionnaire revealed interesting variations within schools, showing diverse pockets of policy in this local arena.¹¹² Out of 41 replies, only 11 secondary schools provided HIV/AIDS education at all stages, with some respondents believing that the topic was unsuitable for younger children. Only 15 schools provided HIV/AIDS education at S1 level (11-12 year olds). Furthermore, schools had chosen to locate HIV/AIDS education in a range of curricular areas. These included discussions in biology, geography and history lessons as well as periods devoted to religious and social education. Methods of presentation also varied considerably between schools, ranging from worksheets and visual presentation to the use of outside speakers brought in to stimulate discussion.

Participants were also asked whether use had been made of the Government's video resource, "Your Choice for Life". Only one school had shown it at S1/S2 level, fifteen at S3/S4 level (13-15 year olds) and eleven at S5/S6 level (16-18 year olds). Out of 26 schools, which had not used it, around half were in the process of

¹¹⁰ *Ibid*, p. 11.

¹¹¹ *Ibid*, GD22/1/2, 'The Take Care Campaign', Letter, Education Department, Lothian Regional Council to Head Teachers of all Secondary Schools, 23 June 1988.

¹¹² *Ibid*, Document, HIV/AIDS Education in Secondary Schools – Feedback from Questionnaire – Circulation Number 316/88.

previewing it, while another two were seeking parental approval. Six schools said they would not use the video. This was for several reasons, including a lack of in-service training, uncertainty around the subject, a preference for face-to-face work, a lack of Scottishness, unacceptability in Catholic schools and 'not suitable for S3/S4'.¹¹³

When asked what types of additional assistance schools would like in order to support their HIV/AIDS education programmes, a number of suggestions were received. These ranged from the need for videos for younger children, to the need for material more suitable to Catholic schools. Some schools also suggested that SHEG's health education ethos, based on a 'healthy lifestyle' approach to understanding risks and disease would be appropriate.

Responses to the questionnaire informed the content of the 'Take Care' School Pack. The main aim was to provide easily accessible materials suitable for use with pupils of school leaving age. The Pack was viewed as an interim measure until the national material that was being produced by the Strathclyde Health and AIDS Project in Education (SHAPE) became available.¹¹⁴ Therefore, the materials were not designed with any particular curricular slot in mind. The long-term intention remained to integrate teaching about HIV/AIDS within a broader health education framework. Copies were sent to 52 state schools as well as independent schools in the Lothian Region, supported by a two-day HIV/AIDS awareness-training course for teachers.¹¹⁵

¹¹³ *Ibid.*

¹¹⁴ *Ibid.* GD24, B9, Document, 'Take Care – A Pack for Schools on HIV/AIDS', October 1988.

¹¹⁵ *Ibid.* B19, HIV/AIDS Back Up Services Resource Folder, Document, *Take Care Campaign Report*, (December 1988 – November 1989), p. 10.

The Introduction of the 'Take Care' school pack made it clear that the decision about how to teach about HIV/AIDS was up to schools and individual teachers, but suggested ways in which this may be implemented. This included providing pupils with basic information about AIDS, addressing fears and worries about AIDS, clarifying attitudes to AIDS, encouraging responsible behaviour and developing attitudes and skills necessary to prevent the spread of HIV and AIDS.¹¹⁶ The packs relied on participative methods involving group discussions and case studies to help pupils make informed decisions and review the options available to them.¹¹⁷

The 'School Pack' was supplemented with an information leaflet about HIV/AIDS, which was distributed to 80,000 parents. A conference, attended by parents, was also held in Edinburgh's Usher Hall, in October 1989, about the AIDS crisis. A spokesman for the LRC's Education Department stated that the 'council's AIDS education strategy so far ha[d] won considerable parental approval and the support of church representatives'.¹¹⁸ However, not all church representatives in Edinburgh agreed. A secondary education adviser for the Catholic Church condemned the pack as providing unsound Christian education that lacked any moral content with respect to chastity.¹¹⁹ It is not clear how many schools chose not to use the pack. Concern was expressed by the CAMO of the LHB that 'some Lothian schools [were] not taking advantage of the information and education packs which [were] being provided for them'.¹²⁰

¹¹⁶ *Ibid*, B9, 'Take Care – A Pack for Schools on HIV/AIDS', October 1988.

¹¹⁷ *Ibid*.

¹¹⁸ D. Smith, 'Spelling Out Drug and Sex Dangers', *Edinburgh Evening News*, 26 April 1989.

¹¹⁹ LHSA, EUL, GD22/19/7, 'The Take Care Campaign', Document, 'Take Care – Lothian Health Board Campaign to Combat the Spread of HIV', n.d.

¹²⁰ D. Forsyth, 'AIDS is Ignored', *Edinburgh Evening News*, 21 December 1989.

The evidence presented in this chapter has demonstrated that, by the late 1980s, the policy response to AIDS in Edinburgh became more liberal as compared to previous responses, particularly with respect to the introduction of wider needle exchange facilities, methadone maintenance therapy, free condoms and 'safe sex' education material. This was a response to ongoing concerns about the heterosexual spread of the disease, amid predictions that as many as 2000 people in Edinburgh could be infected already. The response was also shaped by criticisms from the ACMD, particularly over the lack of response to drug misuse and AIDS within psychiatry and general practice. The extent to which these measures were sustained in the early 1990s will be discussed in the next section.

PART FOUR – THE RESPONSE TO AIDS IN EDINBURGH - 1990-1994

Part Four of this thesis explores developments in response to AIDS in Edinburgh from the early 1990s, following the publication of the Second McClelland Report. Chapter 9 shows that continuing concern over the heterosexual spread of the disease underpinned a liberal response with respect to health education information and material and prophylactics; a response focussing on specific groups such as female prostitutes. However, as will also be shown, there were a number of moral, legal and financial constraints which acted to restrict this more liberal approach.

Chapter 10 concentrates on the response to AIDS in the early 1990s with respect to drug misuse and testing and screening for HIV. This also confirms that the response was dominated by concerns over the spread of AIDS into the wider heterosexual population. ‘Harm minimisation’ policies became popular both outside and inside Scottish prisons, representing a growing shift in attitude by the Scottish Office. In addition, new testing and screening initiatives mirrored national initiatives, particularly with respect to anonymous testing, antenatal screening and guidelines for contact tracing.

CHAPTER 9 - ARE YOU STILL TAKING CARE? - 1990-1994

This chapter focuses on the response to AIDS in Edinburgh from 1990 to 1994. Particular attention is given to shifts in policy response, following the publication of the Second McClelland Report. Developments in care and treatment strategies from 1990 are analysed and followed by an examination of the expansion of health education initiatives to show the extent to which a liberal approach continued amid ongoing concerns about the threat of heterosexual spread of disease, particularly from high-risk groups. Also discussed is the contribution of local epidemiology to shaping the policy response. However, it will also be shown that a number of constraints prevented the extent of liberalism adopted within health education measures.

The Second McClelland Report - 1990

In 1990, the Scottish Home and Health Department (SHHD) created a Working Group following the recommendations of the Tayler Committee. Chaired by Dr Brian McClelland, this group compiled and published the Second McClelland Report containing AIDS projections to the end of 1993 in Scotland.¹ As with the other SHHD Working Groups, a number of the members of this Working Group were Edinburgh based, (four out of ten). These included McClelland, George Bath, Graham Bird, an immunologist, and Robert Covell, who had served in the infectious disease division of the SHHD at the start of the AIDS epidemic and was on the first McClelland Committee as the SHHD representative. He was now a Senior Research Fellow at the Royal Infirmary.

¹ Scottish Home and Health Department, *Acquired Immune Deficiency Syndrome in Scotland – Projections to the End of 1993: Report of a Working Group* (SHHD, August 1990).

The Second McClelland Report predicted that fewer cases of AIDS would occur in Scotland. This was thought to be due to changes in behaviour amongst homosexual and bisexual men, to progression to AIDS in drug misusers being slower than anticipated because of their comparatively young age, and the use of prophylactic treatment at the early stages of disease, dating from around 1987.² In England and Wales similar predictions with respect to AIDS cases were made in comparable reports. The Cox Report on Short-Term Predictions of HIV Infection and AIDS had been published in 1988 and an update was presented in 1990 by the Day Committee.³

However, the prediction of fewer AIDS cases showed some variance in Scotland, with Lothian continuing to show the highest number of predicted cases. For example, the Report predicted that 280 new cases of AIDS would occur in 1993, 170 of which would occur in Lothian, amongst intravenous drug misusers.⁴ The Lothian Health Board (LHB)'s own statistics, compiled in 1988, made similar predictions to those in the Second McClelland Report, indicating a continued rise in the number of drug injectors developing AIDS.⁵ On the basis of these figures the LHB estimated that 45 hospital beds would be required by 1991, rising to 125 in 1994.⁶

Provision of Care and Treatment for AIDS/HIV Sufferers

² *Ibid*, p. 5.

³ Department of Health and Social Security, *Short Term Prediction of HIV Infection and AIDS in England and Wales: Report of a Working Group* (London, 1988); Communicable Disease Surveillance Centre, *Acquired Immune Deficiency Syndrome in England and Wales to the end of 1993: Report of a Working Group* (CDSC, January 1990).

⁴ Scottish Home and Health Department, *Acquired Immune Deficiency Syndrome in Scotland – Projections to the End of 1993: Report of a Working Group*, (SHHD, August 1990) p. 22.

⁵ LHAS [Lothian Health Services Archive], EUL [Edinburgh University Library], GD24, B19, HIV/AIDS Back Up Services Resource Folder, Lothian Health Board, *AIDS in Lothian – Time to Take Care - Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending 31 March 1989), Appendix 1.

⁶ *Ibid*, C2, D5, (2.28.0), General Management – AIDS and Drug Misuse Meetings – Letter, R. Lewis and G. Bath to J. Lusby, 18 December 1990.

By 1990, bed provision continued to be a cause for concern for those involved in the care and treatment of AIDS sufferers. The Special AIDS Unit remained unfinished, due to the various delays mentioned in Chapter 7. 1990 was a period of severe financial crisis for the LHB, as for other HBs (Health Boards), as they readied themselves for the advent of changes being introduced by the 1989 White Paper, *Working for Patients*.⁷ The General Manager and Chairman resigned over the matter.⁸ It had become apparent to the LHB management that AIDS funding from the SHHD would not be sufficient to provide adequate services for the treatment and prevention of AIDS/HIV.⁹ AIDS money from the SHHD had not been allocated on the basis of the number of AIDS or HIV cases being treated by each Health Board (HB) but on the basis of other calculations which included costs of prevention measures.¹⁰ This method had been devised by the SHHD in order to provide a more even spread of funding to HBs outwith Greater Glasgow, Lothian and Tayside. It meant that Edinburgh had only received 39% of funding for 1990-91, despite having 60% of HIV cases, as some statutory workers took the opportunity to report to the local media.¹¹

In 1991, a National Audit Office Report on *HIV and AIDS Related Health Services* criticised the funding of services and stated that resources needed to be targeted more

⁷ C. Bennett and E. Ferlie, *Managing Crisis and Change in Health Care – The Organizational Response to HIV/AIDS* (Buckingham, Open University Press, 1994), p. 27.

⁸ LHASA, EUL, C6, D4 (19.0.0), AIDS and Prostitution (Part 1), Letters G. Bath to G. B. G. Lomas, 6 April 1990 and D. J. Piggott to G. Bath, 18 August 1990.

⁹ *Ibid.*, GD24,, B3, Lothian Health Board, *AIDS in Lothian: Facing the Facts - Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending 31 March 1990), Appendix 3.

¹⁰ NAS [National Archives of Scotland], SOE12/521, Minutes, C. M. A. Lugton to M. Forsyth, 21 July 1989.

¹¹ M. Harker, 'Rent Boys in AIDS Shock', *Edinburgh Evening News*, 28 June, 1989.

closely at areas of greatest need.¹² Subsequently the SHHD decided to increase its funding for HIV/AIDS and drug services in Lothian for that year. George Bath announced in the 1992 LHB's Annual Report on AIDS that during 1991-1992 there was 'considerable expansion of HIV/AIDS and drugs services' from the SHHD, allowing the Board to implement developments that had been planned before the financial hardship.¹³ Compared with the previous year's LHB funding from the SHHD for HIV/AIDS and drug misuse services this represented over £2.5 million.¹⁴

Special AIDS Unit Edinburgh

By this time the Special AIDS Unit had finally opened, some five years after the initial proposals were submitted to the LHB by Infectious Diseases specialists. In 1992, the LHB's Annual Report on AIDS stated that, whilst the number of admissions to the Unit for HIV/AIDS-related illness continued to rise, the average length of stay was falling.¹⁵ This was due in part to changes in therapies and the introduction of District Nurses trained to care for HIV positive patients at home.¹⁶

Milestone House

¹² National Audit Office, *HIV and AIDS related Health Services* (London, HMSO, 1991).

¹³ LHSA, EUL, GD24, B4, Lothian Health Board, *HIV in Lothian: Building Together 1992 - A Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending 31 March, 1992), p. 27. A total of £17.6 million was allocated in 1991-92 to HBs in relation to HIV and AIDS-related services. See, NAS, HH61/1523, 'HIV and AIDS – Scotland – Current Situation and Developments – December, 1991'. In recognition of the extra burdens arising from HIV infection and AIDS, the allocation to HBs rose to £19 million in 1992-93. See, *Ibid*, Minute J. T. Brown to Dr Steel, 25 September 1992.

¹⁴ See, LHSA, EUL, GD24, B4, Lothian Health Board, *HIV in Lothian: Planning the Future 1991 – A Report in Response to the AIDS (Control) Act 1987*, (LHB, Year Ending 31 March, 1992), p.34; Lothian Health Board, *HIV in Lothian: Building Together 1992 - A Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending 31 March, 1992), p. 27.

¹⁵ *Ibid*, p. 18.

¹⁶ *Ibid*. For a more detailed account of the types of medical treatment such as Zidovudine (also known as AZT) provided to HIV/AIDS sufferers from the mid 1980s onwards at the City Hospital see, R. Brett, *HIV – The Edinburgh Epidemic* (MD Thesis, University of Edinburgh, 1995). For a wider history of the City Hospital see, J. A. Gray, *The Edinburgh City Hospital* (East Linton, Tuckwell Press, 1999).

The AIDS hospice, 'Milestone House' also opened in 1991, after the Waverley Care Trust had reached a compromise with city council leaders over an appropriate site within the City Hospital grounds, not far from the Special AIDS Unit. This was hailed as the first purpose-built AIDS hospice in the UK and provided a 20-bedded unit for respite, convalescent and terminal care.¹⁷ The accommodation consisted of four bungalows linked to a central area. Each bungalow contained three single rooms and one double room, all with en-suite facilities. Provision was made for men, women and children and their carers and families.¹⁸

Concerns over the Heterosexual Spread of HIV

The Second McClelland Report also warned of the dangers of heterosexual transmission and stated that Scotland was entering a more complex phase of the disease, composed of a series of separate but interlinked epidemics in transmission categories such as injecting drug misusers and heterosexuals.¹⁹ The Scottish Office endorsed these findings in July 1990 by stating that:

Although the updated predicted incidence of AIDS in Scotland is lower than previously calculated, the potential for widespread dissemination of HIV still exists, particularly among heterosexuals and injecting drug misusers. Equally it is essential that behaviour changes already evident in the homosexual community are maintained and reinforced.²⁰

¹⁷ LHASA, EUL, GD24, B7, Document, 'Milestone House – The Only Hospice and Continuing Care Unit in Scotland for People with AIDS and HIV', (Edinburgh, Waverley Care – An AIDS Trust, 1991).

¹⁸ *Ibid*, B10, Lothian Health Board, *HIV/AIDS in Lothian – Planning the Future 1991 - A Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending 31 March 1991), p. 55.

¹⁹ Scottish Home and Health Department, *Acquired Immune Deficiency Syndrome in Scotland – Projections to the End of 1993: Report of a Working Group* (SHHD, August 1990), p. 5.

²⁰ NAS, HH61/1518/1, Scottish Office News Release, July 1990.

Concerns over the heterosexual spread of disease led to the formation of a new AIDS Task Force (ATF), in July 1991, chaired by Michael Forsyth in order to examine current policy and advise for the future. The Report, published in 1992, warned that heterosexual transmission was a real threat in Scotland and that this could become the main transmission route for HIV infection.²¹ It stated that intravenous drug misusers could transmit the virus by indiscriminate sexual activity undertaken either under the influence of drugs or in order to fund their drug habit. Although needle exchanges had possibly reduced intravenous transmission amongst drug misusers, this group as a whole were perceived to have chaotic lifestyles and be more prone to unreliability, poor compliance and breakdown in resolve.

As with many of the SHHD Committees on AIDS, the ATF included several members from the Edinburgh HIV/AIDS policy community, including George Bath, Roy Robertson, Maureen Moore, Chief Executive of Scottish AIDS Monitor (SAM), and John Chant, Director of Social Work. George Bath had informed a meeting of the Lothian HIV/AIDS Forum that the impetus for the formation of the ATF was the anticipation of a 'heterosexual epidemic' and therefore its primary emphasis was on prevention.²²

The Chief Medical Officer's Annual Report for 1991-1992 said it was 'deeply worrying that the proportion of those newly diagnosed as HIV positive, who appear to

²¹ Scottish Home and Health Department, *HIV and AIDS in Scotland – Prevention the Key*, Report of Ministerial Task Force, March 1992, p. 12.

²² LHSA, EUL, GD24, C5, D3 (2.2.1), Regional AIDS Group Minutes and Agendas, Part 5, Minutes of Lothian HIV/AIDS Forum, 27 August 1991.

have contracted the infection by heterosexual intercourse is high and rising'.²³ These cases were concentrated predominantly in the south-east of Scotland, which covered Edinburgh and Dundee.

Local Epidemiology and Research

While the national (Scottish) reports expressed concern about the threat of heterosexual spread, local epidemiological accounts of the transmission of HIV via heterosexual contact was also an important factor in shaping the response at this time. For example, LHB's AIDS Report for 1990 stated that, from a total of 91 HIV positive cases reported up to the end of March 1990, 19 cases (14 female and 5 male) were found to have acquired the infection through heterosexual contact. This represented a proportionate increase of 58% upon the previous year.²⁴ The AIDS Team claimed that they could find no easy answer for the increase in such cases and, although the statistics had to be treated with a degree of caution, they believed they were a reflection of the 'long awaited and much feared 'third wave' of large-scale heterosexual infection' in Lothian.²⁵

By this time, figures on the transmission of HIV via needle sharing (the second wave of infection in Lothian) were beginning to drop.²⁶ This was thought to be due to the work of needle exchange schemes and the provision of substitute prescription drugs such as oral methadone.²⁷ Nonetheless, continuing anxiety remained about regression

²³ NAS, HH61/1523, Chief Medical Officer's Annual Report for 1991 – September 1992.

²⁴ LHSA, EUL, GD24,, B3, Lothian Health Board, *AIDS in Lothian: Facing the Facts - Report in Response to the AIDS (Control) Act 1987*, Year Ending 31 March 1990, p. 5.

²⁵ *Ibid.*

²⁶ *Ibid.*

²⁷ A. Crow, 'Sex is Safer on the Bus', *Scottish Daily Record*, 14 November 1994, p. 17.

into unsafe behaviour amongst drug misusers and concern that those heterosexual IV drug misusers who were HIV-positive would continue to practise unsafe sex, including prostitution, thus creating the potential to transmit the virus to the wider population.

In subsequent reports increases in the transmission of HIV by heterosexual spread were duly noted. In 1991, the AIDS Team claimed that the LHB would be foolish if they ‘failed to regard it [heterosexual infection of HIV] as our number one prevention priority’.²⁸ In 1994, there had been a slight reduction in the number of HIV-positive cases through heterosexual spread. However, the LHB’s AIDS Report warned:

We have stated before our continued belief that the danger of a heterosexual epidemic of major proportion, is significant. If such an event occurs in the UK, there is every scientific reason to believe that the greatest probability is that it will happen in Lothian.²⁹

This statement was influenced, to some degree, by the findings of Brettle and Robertson, as mentioned in Chapter 8, that many HIV positive drug misusers had yet to reach stage two of their infectious period, where the risk for spread to their heterosexual partners would increase. In addition, other local research findings had also confirmed fears about Edinburgh’s potential for a heterosexual epidemic. For example, research work, carried out by the University of Edinburgh’s Alcohol Research Group, interviewed 205 sex workers (102 male and 103 female) in

²⁸ LHSA, EUL, GD24, B10, Lothian Health Board, *Planning for the Future – HIV/AIDS in Lothian - Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending March 1991), p. 4.

²⁹ *Ibid*, B3, Lothian Health Board, *Strategies for Survival – HIV/AIDS in Lothian - Report in Response to the AIDS (Control) Act 1987* (Year Ending 31 March 1994), pp. 33-4.

Edinburgh during the late 1980s.³⁰ This study, which was funded by the Medical Research Council (MRC), revealed that 20% of respondents admitted to intravenous drug misuse and a minority stated that they rarely or never used condoms. Some of the respondents claimed that there was a demand for unprotected sex from clients and that they could charge more for this service. Moreover, it was also found that the majority of respondents who had a regular partner rarely or never used condoms when they engaged in penetrative sex with that person. The researchers concluded that 'people who buy and sell sexual services should be priority targets for health education strategies to reduce their risk of AIDS'.³¹

Some fellow researchers in the field were shocked by these results, especially the high number of rent boys (male prostitutes) operating in the City who did not always use protection.³² The local media were quick to report the findings and continued to reinforce panic about the threat of AIDS from sexual transmission, especially prostitution. For example, the *Edinburgh Evening News* reported that Edinburgh was facing a new AIDS threat from an expanding 'sex industry'.³³ Claims were made by some local councillors that the increase in 'rent boys' was due to government changes in young people's housing benefits, which forced some into heterosexual or homosexual activity for money to pay for their accommodation.³⁴ As with some earlier contributors to the AIDS policy-making process, councillors attempted to stimulate government action through media exposure.

³⁰ R. Morgan-Thomas, M. A. Plant, M. L. Plant and D. I. Sales, 'Risks of AIDS Among Workers in the 'Sex Industry': Some Initial Results from a Scottish Study', *British Medical Journal*, 15 July 1989, pp. 148-9.

³¹ *Ibid.*

³² See, for example, LHSA, EUL, GD24, C6, D4, (19.0.0), AIDS and Prostitution (Part 1), Letter, G. Bird to R. Morgan Thomas, 2 October 1989.

³³ M. Harker, 'Rent Boys in AIDS Shock', *Edinburgh Evening News*, 28 June 1989.

³⁴ *Ibid.*

The Edinburgh District Council's Environmental Health Committee, believed that the 'education of young people was absolutely essential in any coherent strategy for prevention and had to be the 'number one' priority for funding in the field of HIV/AIDS, particularly in Lothian, where heterosexual spread of the virus would soon become the major route of transmission'.³⁵ In addition, the LRC's Policy and Resources Committee had stated in its AIDS Progress Report of 1990 that, in the absence of a vaccine or cure, it was crucial that the general 'Take Care' campaign be given every prominence and priority despite the LRC's financial climate.³⁶

Health Education

When the LHB had its funding increased in 1991 the need for some of the new AIDS money to be applied to new health education initiatives was considered to be of high priority. These measures demonstrated the extension of a liberal policy response in Edinburgh with respect to HIV/AIDS education about 'safe sex' and prophylactic measures such as condom supply. However, epidemiological and research findings were not the only factors to determine the course that HIV/AIDS education policy took during the early 1990s. Other factors such as legal and moral judgements, at both local and national level, influenced the policy process and to a certain extent constrained the degree of liberalism some policy makers would have hoped for, especially with respect to the issue of prophylactic supplies for prostitutes. These

³⁵ LHSA, EUL, C5, D2 (2.2.0), Regional AIDS Group – General (Part 4), Letter, Director of Administration to G. Bath, 30 July 1991.

³⁶ *Ibid*, Document, 'Lothian Regional Council – Policy and Resources Committee – AIDS Progress Report', September 1990, p. 3. During the early 1990s the LRC also faced a period of financial hardship and it was uncertain at this time whether it could commit itself to the renewal of health education initiatives relating to HIV/AIDS. See, *Ibid*, Letter G Bath to G. M. Bowie, LRC, 31 May 1991.

constraints also revealed a number of tensions between agencies from the statutory and voluntary sector and illustrate how attempts at collaboration were at times strained over conflicts between the protection from infection and the control of criminal behaviour.

Are You Still Taking Care?

From 1991, the LHB and the LRC had dedicated considerable effort and resources into furthering the 'Take Care' campaign, emphasising the risks from heterosexual transmission. They reinforced the 'safe sex' message using a range of media outlets, which included adverts in newspapers, on the radio, in the cinema, inside and outside buses and even at football matches and pop concerts. Some efforts received worldwide recognition, such as the cinema advert, entitled 'Use a Rubber', which won an award for its design.³⁷ Indeed, the ATF had recommended that health education agencies 'take a proactive stance in their contacts with the media', in order to disseminate health education.³⁸

In addition, a second mail drop to every household in Lothian occurred in December 1991 as an 'Update' to keep Lothian's HIV/AIDS problem prominent in the minds of its citizens.³⁹ This included information on the estimated incidence of HIV infection through heterosexual transmission amongst men and women in Lothian (1 in 100 men and 1 in 250 women were said to be HIV positive).⁴⁰ Advice was also given on

³⁷ LHSa, EUL, GD22/1/6, Newsclippings, 1993.

³⁸ Scottish Home and Health Department, *HIV and AIDS in Scotland – Prevention the Key*, Report of Ministerial Task Force (SHHD, March 1992), p. 33.

³⁹ LHSa, EUL, GD24, B10, Lothian Health Board, *Planning for the Future - Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending 31 March 1991), p. 14.

⁴⁰ *Ibid*, GD22/6/5, "Take Care" Campaign, Mail Drop, Update 1991.

condom use and emphasis placed upon the importance of having sexual relations only with a faithful partner.

Efforts to boost the 'Take Care' campaign occurred again in 1994 when a total of £50,000 was spent on a new campaign message, which now highlighted two possible ways of taking care, by using condoms or simply saying 'no'.⁴¹ The rationale behind the latter message was the belief that many women, if empowered, would say 'no' to casual sex. An evaluation survey of the 'Take Care' campaign in 1993 had revealed that many saw it merely as a campaign to promote the use of condoms as a means of preventing HIV/AIDS.⁴² Other 'Take Care' choices, such as choosing to have a relationship without sexual intercourse, were not identified by any respondents who took part in the survey. Therefore, greater emphasis was placed on the phrase 'Taking Care', with messages such as 'Have you worked out what taking care means for you?' and 'Are you still taking care?'.⁴³ These messages were promoted to encourage personal reflection within the context of active sexual engagement and, as with previous messages, they were advertised using a range of media outlets, which included a message on 130 Lothian double decker buses.⁴⁴

Promotion of the free availability of condoms continued. These could now be obtained from GPs, (who had previously issued them only to drug misusers), non-statutory drug projects, family planning clinics, university campuses, projects working

⁴¹ C. Holme, 'Warning of Epidemic in Lothian at Launch of Safer Sex Campaign', *The Glasgow Herald*, 16 November 1994.

⁴² LHSa, EUL, GD24, B10, Lothian Health Board Education Department, *Take Care Media Campaign on HIV/AIDS – Evaluation Report – Part 1 – Quantitative Street Survey* (LHB, February 1993), pp. 2-5.

⁴³ *Ibid*, B3, Lothian Health Board, *Strategies for Survival – HIV/AIDS in Lothian – Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending March 1994), pp. 33-4.

⁴⁴ A. Crow, 'Sex is Safer on the Bus! – New Ads Blitz on AIDS', *Scottish Daily Record*, 16 November 1994, p. 17.

with the sex industry and in the toilets of various bars in Edinburgh's city centre.⁴⁵ The C-Card system, run by LHB, was still in operation and extended its free condom service to clients at around 50 outlets throughout the city.⁴⁶

For some, Edinburgh's HIV problem had made the use of condoms a 'regrettable necessity'.⁴⁷ These were the words of a local catholic priest, Father Tom Williams, who was the AIDS Liaison Officer appointed to an HIV/AIDS action team to promote education about the virus. In a press statement, Williams claimed that, while the Christian ideal was that sex should take place only within marriage, it had to be accepted that the behaviour of many people did not live up to that ideal.⁴⁸ Therefore, his view was that, if someone was going to engage in sex, then he would say 'Take Care' and use a condom.⁴⁹ An Official Spokesman for the Catholic Church stated that Father Williams message was acceptable because he was speaking to 'non-church people'.⁵⁰ Meanwhile, the Church of Scotland remained of the view that they would take every opportunity to emphasise the teachings of chastity before marriage and fidelity within marriage. They firmly believed that non-adherence to these teachings could increase the risk of infection.⁵¹ Similarly, the Free Church of Scotland expressed concern that HIV/AIDS educational material was damaging in that it assumed immorality as the norm.⁵² Some churches in Scotland saw the AIDS

⁴⁵ LHSA, EUL, GD24, B10, Lothian Health Board, *Planning for the Future - Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending 31 March 1991), p. 34.

⁴⁶ *Ibid*, GD22/17/72, See, C-Card Service Project profile inserted inside *Meridian*, 72, September 1995. *Meridian* was launched by the LHB in September 1989 as a monthly back up information sheet for HIV/AIDS workers, bringing them up to date with forthcoming events, resources and new developments.

⁴⁷ 'Condoms Regrettable Necessity, He Says', *Edinburgh Evening News*, 4 December 1993.

⁴⁸ *Ibid*.

⁴⁹ *Ibid*.

⁵⁰ *Ibid*.

⁵¹ The Church of Scotland, *General Assembly Report*, (1992), p. 331.

⁵² Free Church of Scotland, *The Principal Acts of the General Assembly*, (May 1991), p. 81.

epidemic as a catalyst for change, since they considered AIDS to be 'the key to a revival of religion' in the country.⁵³

The Sex Industry

Concerns over the spread of HIV through heterosexual transmission were also reflected in new health education measures that targeted specific groups, particularly those working in the sex industry. One of the new initiatives introduced was the formation, in 1991, of the Scottish Prostitutes Education Project (Scot-PEP), a peer-led education group run by prostitutes and ex-prostitutes for prostitutes. It offered drop-in facilities, outreach medical services and information and advice about health in relation to STDs and drug use, in addition to a range of items including free condoms.⁵⁴ The project aimed to offer non-judgmental services to both male and female prostitutes.⁵⁵ Some of Scot-PEP's funding came from the LHB and its new premises in the City centre were leased from the LHB.⁵⁶

A similar endeavour, the Centenary Project, concentrated on drug-addicted female prostitutes, which began in 1987 as an outreach project in Leith and received its funding from the Women's Guild of the Church of Scotland, whose centenary celebrations provided £120,000 towards running costs.⁵⁷ By 1990, services were expanded to offer drop-in facilities in Leith, which included the provision of 'safe sex' information and condom distribution. In addition, this project had strong links

⁵³ *The Scotsman*, 17 January 1992; also quoted in *Gay Scotland*, 62, May 1992, p. 7.

⁵⁴ LHSa, EUL, GD22/17/30, see, Scot-PEP profile inserted inside *Meridian*, 30 March 1992.

⁵⁵ *Ibid.*

⁵⁶ *Ibid*, GD24, C6, D4 (19.0.0), AIDS and Prostitution (Part 1), Minute, G. Bath to G. Brechin, 1 February 1991.

⁵⁷ *Ibid*, GD22/17/45, See, Centenary Project profile inserted inside *Meridian*, 45, June 1993. See also, The Church of Scotland, *General Assembly Report*, (1994), p. 446.

with the Genito-Urinary Medicine (GUM) Department, whence staff offered a medical outreach service, including two clinics each week for STD screening. The project was managed by the Board of Social Responsibility of the Church of Scotland and, by October 1991, LHB took over full funding of the project.⁵⁸ The Centenary Project differed in philosophy from Scot-PEP, in that in addition to supporting a harm minimisation approach it also supported initiatives, that empowered women to move out of prostitution, including the route of religious conversion.⁵⁹

Other projects included the LHB's Harm Reduction Team (HRT), which came into existence in 1991 and offered advice on 'safe sex' and safe drug use at one of the City's needle exchange schemes. As patterns of drug misuse changed in the 1990s their remit broadened to include safer sex work with non-injecting drug users.⁶⁰ By 1994, the HRT had started to target male sex industry workers.⁶¹ This Team also administered LHB's budget for the supply of condoms to numerous outlets, which included the facilitation of the C-Card scheme.⁶²

National Health Education Measures

Running concurrently with local health education measures, a number of initiatives were introduced at the national level, which also emphasised the risks of sexual spread of HIV. For example, the new Health Education Board for Scotland (HEBS)

⁵⁸ *Ibid.*

⁵⁹ *Ibid.* See also LHSA, EUL, GD24, C6, D4 (19.0.0), AIDS and Prostitution (Part 1), Letter G. E. Bath to R. Morgan Thomas, 10 October 1989.

⁶⁰ LHSA, EUL, GD22/17/63, See, The Harm Reduction Team Project profile inserted inside *Meridian*, 63, December 1994.

⁶¹ *Ibid.*, GD24, B3, Lothian Health Board, *Strategies for Survival – HIV/AIDS in Lothian - Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending 31 March 1994), pp.33-4.

⁶² *Ibid.*, GD22/17/63, See, The Harm Reduction Team Project profile inserted inside *Meridian*, 63, December 1994.

identified HIV/AIDS and drug misuse amongst their main national priorities. HEBS had been formed in April 1991 to replace the Scottish Health Education Group (SHEG). Within a year of its implementation, the HEBS budget had increased from £5.36 million in 1991/92 to £6.44 million in 1992/93, reflecting the importance attached to health education by the Scottish Office. The HEBS produced a magazine style publication named, *The Issue*, during the early 1990s.⁶³ This was targeted at 16-18 year olds and provided information on love, sex and relationships. The aims included raising awareness about the modes and patterns of the spread of HIV and encouraging young people to assess their own level of risk within the context of a healthy lifestyle.

AIDS Education in Schools

During the 1990s, Scottish Office also became more involved in promoting AIDS education in schools. The Scottish Education Department (SED) booklet on facts about HIV and AIDS for teachers, lecturers and youth workers was updated and stressed the importance of avoiding promiscuous sex and anal intercourse. This warned that heterosexual intercourse could transmit the virus from man to woman and from woman to man.⁶⁴ In similar terms to the HEBS guidance, the SED booklet recommended the need for schools to raise awareness about HIV/AIDS through programmes of social and health programmes that chose to emphasise healthy approaches to living rather than adopting shock horror methods.⁶⁵ By this time, the Strathclyde project had finally published its joint guidelines with the SED on health

⁶³ NAS, HH61/1495/1, 'HIV and AIDS – The Role of HEBS – A Briefing Paper for the AIDS Task Force', 6 August 1991.

⁶⁴ LHSA, EUL, GD24, B5, Scottish Education Department, *A Guide for the Education Services in Scotland – HIV + AIDS – Facts for Teachers, Lecturers and Youthworkers* (SOED, 1991), pp. 6-7.

⁶⁵ *Ibid*, p. 12.

and social education in Scotland, which included a section on AIDS Education. The package, entitled the Strathclyde Health and AIDS Project in Education (SHAPE), covered all stages of education from Pre-school to 16 years plus.⁶⁶ As with much of the other Scottish health education material, this chose to promote positive attitudes to health and social well-being.

A separate section on AIDS, 'The Escape-AIDS Pack', was designed for use with children aged 5-16 years, with activities appropriate to their stage of development. The material for those in the 5-8 age group consisted of information on basic hygiene skills. 8-10 year olds were to be introduced to AIDS through the concept of infection by looking at 'germs'. Meanwhile, 10-14 year olds learned about AIDS during activities on the workings of a healthy immune system. The material for 14-16 year olds was designed as a complete package for young people to explore the implications of AIDS. Strathclyde Regional Council (SRC) claimed that the essential message being taught to children was that AIDS could be avoided if sex was reserved for a stable relationship such as marriage. The Scottish churches were asked to comment on the material. Their beliefs remained the same, that sex outside marriage was against church teachings.⁶⁷ One church in particular, the Free Church of Scotland, believed there were serious deficiencies in the material, especially as the pack omitted to advise on the dangers inherent in homosexual practices since, in their view the word 'partner' was used implicitly to condone homosexual relationships and advice was given just as freely to those not prepared to stick with one partner.⁶⁸

⁶⁶ Copy available at Health Scotland Library, Canaan Lane, Edinburgh.

⁶⁷ A. Forbes, 'New Fact Of Life Will Be Presented Gently', *The Scotsman*, 22 December 1989.

⁶⁸ The Free Church of Scotland, *The Principal Acts of the General Assembly* (Edinburgh, May 1992), p. R71. Interestingly, Scottish schools have been advised to give pupils advice on homosexuality from August 2006. Current guidelines were deemed to be "heterosexist". The Catholic Church in Scotland

By 1990, a number of resources were available to Lothian schools. These included the 'Take Care' pack and the 'Escape-AIDS' pack. A new video resource had also been produced by the LRC's education department, directed at 13-14 year old pupils. Furthermore, an AIDS game known as 'Choices', based on the 'Take Care' theme, was also launched and made available to schools. All these materials set out to avoid shock horror methods or overt moralising in their message, and they became the principal source of material available to Edinburgh and Lothian's educational establishments.

In addition, the LRC's HIV/AIDS Education Team began to focus upon working directly with school pupils in order to learn how best to enable individuals to make their own choices about 'safe sex'. Conferences for senior secondary pupils were aimed at giving them the opportunity to speak confidentially in a small group setting and to consider HIV/AIDS in relation to their own behaviour. These conferences were often delivered in collaboration with voluntary agencies such as the Brook Advisory Centre, and, by 1992, seminars had been held in 75% of secondary schools.⁶⁹ The HIV/AIDS Education Team had been involved with in-service training of teachers in over 90% of primary schools. The training aimed to keep teachers supplied with a constant flow of new information and to encourage the incorporation of HIV/AIDS education into different parts of the school curriculum.⁷⁰

condemned the move as 'appalling, outrageous and utterly unnecessary'. See K. Foster, 'Schools Told to Give Pupils Gay Sex Advice', *Scotland on Sunday*, 21 May 2006.

⁶⁹ LHSa, EUL, GD22/17/32, See, the Education Department's HIV/AIDS Team Project Profile inserted inside *Meridian*, 32, May 1992.

⁷⁰ *Ibid*, GD24, B4, Lothian Health Board, *HIV/AIDS in Lothian: Building Together - Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending 31 March 1992), p. 15.

Although epidemiology and local research studies were significant in the context of promoting some of the above measures, other factors shaped policy formation during this period. At times, these factors operated to constrain the liberal line taken and to restrict the way in which educational literature and prophylactics could be distributed and developed. This is especially evident when examining controversial policies concerning the provision of health education and condoms to those in the sex industry.

In 1989, the RAG set up a Working Group on prostitution after the findings from the previously mentioned study carried out by the Alcohol Research Group.⁷¹ Part of the remit was to enter into discussions with representatives from the local criminal justice system, which included an Assistant Procurator Fiscal, an Assistant Chief Constable and a Reporter to the Children's Hearing Panel, in order to clarify the legal position of AIDS workers under Scottish Law. A primary concern of staff operating in the field was that condoms, distributed by AIDS agencies could, in law, be used as circumstantial evidence in the prosecution of women for soliciting. While the Procurator Fiscal and the Police were sympathetic to a flexible operation of the law, they did not support its revision, thus leaving the legal status of the supplying of condoms to the sex industry as highly vulnerable.⁷²

The criminal justice system at the national level expressed similar views. For example, the Scottish ATF Report noted that the police service in Scotland were generally sensitive to public health considerations in this context, but the use of condoms, as evidence of soliciting, was indeed left to the discretion of the Procurator

⁷¹ *Ibid*, C5, D3 (2.2.1) Regional AIDS Group Agenda and Minutes (Part 5), Draft, 'Regional AIDS Group Sub Group on Sex Industry', 24 May 1991.

⁷² *Ibid*.

Fiscal.⁷³ In response, the ATF announced that they wished to encourage the continuation and development of the sensitive policing of prostitution, so that the sex industry were not put off using condoms.⁷⁴

Tensions Between the Voluntary and Statutory Sector

Conflicts between the local statutory sector and the voluntary sector also emerged over the issue of prophylactic items to be supplied to the sex industry in order to reduce the risk of HIV. These tensions were evident between the LHB and Scot-PEP and had an impact upon policy development. They not only reflected the controversial nature of the items requested by Scot-PEP for prophylactic purposes, but were intertwined with wider concerns shared by some in the statutory sector about the ability of those responsible to manage Scot-PEP itself.

The LHB believed that Scot-PEP had a crucial role in the prevention of widespread HIV infection and had committed support for the development of the programme.⁷⁵ Scot-PEP sought to encourage sex industry workers to use condoms and other items for safe oral and anal sex. However, the extent of their work became limited by funding restrictions. In May 1992, Scot-PEP wrote to LHB asking for authorisation and extra funding for a further range of items for use in workshops.⁷⁶ These included novelty condoms, dental dams and latex finger sheaths. The intention was to promote a range of safe and sometimes non-penetrative sexual practice amongst prostitutes,

⁷³ Scottish Home and Health Department, *HIV and AIDS in Scotland – Prevention the Key - Report of Ministerial Task Force* (SHHD, March 1992), pp. 66-7.

⁷⁴ *Ibid.*

⁷⁵ LHASA, EUL, GD24, C6, D4 (19.0.0), AIDS and Prostitution (Part 1), Letters G. Bath to G. B. G. Lomas, 6 April 1990 and D. J. Piggott to G. Bath, 18 August 1990.

⁷⁶ *Ibid.*, (1 19.0.0), AIDS and Prostitution (Part 2), Letter R. Morgan Thomas to G. Bath, 6 May 1992.

which would also protect their income.⁷⁷ On this occasion the LHB, whilst citing a previous agreement with Scot-PEP (and other groups) that they were at liberty to spend their budget on condoms and equipment, refused to allocate additional funding for these newly specific items.⁷⁸

The LHB appear to have become concerned about funding what they termed to be 'exotic', items, especially gloves and dental dams. Whilst the financial implications of supplying these types of prophylactics to the sex industry may have played a role in their reluctance, the use of the term 'exotic' by the LHB suggests that either they considered these new 'safe sex' items to be superfluous to the needs of public health, or that they feared the accusation of funding pleasure rather than mere health.

In addition, this reluctance could also have been based on existing concerns about the quality of Scot-PEP's management. Scot-PEP had welcomed the financial support but had been reluctant to have formal administrative involvement from LHB on the grounds that it would deter those in the sex industry from coming forward, due to the illegal nature of their work. The LHB had not been convinced that Scot-PEP could manage their project independently of the statutory sector, especially in view of the time it had taken them to get the project up and running, despite funding from charities and the offer of premises from the LHB. The AIDS Co-ordinator believed that part of the problem was that Scot-PEP was managed by sex industry workers who were untrained and thus 'fairly low on administrative ability'.⁷⁹

⁷⁷ *Ibid.*

⁷⁸ *Ibid.*, AIDS and Prostitution (Part 2), Memorandum, D. Gorman to K. Haigh, 20 August 1992.

⁷⁹ *Ibid.*, Letter, G. Bath to G. Brechin, 1 February 1991.

Tensions between the two agencies increased during 1993, when Scot-PEP was unsuccessful in their tendering bid for sex industry funding from the LHB. The successful bidders were a new group, the Scottish HIV Action (SHIVA) group, that had grown out of the work of the Church of Scotland Centenary Project and the LHB's own Harm Reduction Team. The former worked specifically with female prostitutes while the latter concentrated on male prostitutes. As a result of the LHB's decision Scot-PEP were faced with a period of financial crisis. Martin Plant, Head of the Alcohol Research Group, who had been behind the Scot-PEP initiative wrote strong letters of protest to various people including the SHHD and Lord Fraser, the new Health Minister for Scotland.⁸⁰

Letters of support for Scot-PEP were sent to the LHB and the SHHD from national and international bodies, expressing concern about the decision not to support the bid of a body whose model of prevention had received international acclaim. Thus, for example, representations were received from the National Minority AIDS Council and the National Institute for Prostitution Issues in the Netherlands.⁸¹ In addition, one Labour MP for Edinburgh and a civil servant from the SHHD went as far as to request further information on the LHB's evaluation system.⁸² Scot-PEP believed that one of the assessors for the tendering process had very negative views about key people in Scot-PEP.⁸³ Even in the face of political pressure, the LHB stuck to its decision and

⁸⁰ *Ibid*, Copy Letter, M. Plant, 21 December 1993.

⁸¹ *Ibid*, Fax, P. A. Kawata to J. Baynhan, 13 December 1993; Letter, J. H. Visser to Secretary of State for Scotland, 13 December 1993.

⁸² *Ibid*, Letter, A. Darling to J. Baynhan, 22 February 1994 and W. Davidson to G. Bath, 15 December 1993.

⁸³ *Ibid*, LHB45/1, B1, 'AIDS and Prostitution', Memo, H. Zealley to P. Wilson, 15 December 1993.

stated that the tendering process had been carried out ‘thoroughly, professionally and fairly’.⁸⁴

As noted in Chapter 7, discord between the voluntary and statutory sector had begun to develop by the late 1980s over issues of funding.⁸⁵ The voluntary sector complained of insufficient representation on RAG and the Lothian AIDS Forum (LAF) with a concomitant lack of executive influence. In the case of the RAG, with responsibility of allocating charitable funds, the conflict between voluntary and statutory sector members culminated over a series of discussions over the decision-making process, wherein RAG membership and function came to be re-evaluated. There followed a lengthy exercise, which resulted in a complete restructuring of RAG and LAF in September 1991. The RAG and the LAF were replaced with a three-tier system, which consisted of a Joint Co-ordinating Committee on HIV/AIDS, an HIV/AIDS Management Team and the Lothian HIV/AIDS Forum, which was divided into five functional groupings.⁸⁶ The new arrangements sought to rectify the defects recently identified, to retain some of the characteristics of the old system, and to ‘maintain a multi-agency dialogue on the basis of mutual trust and respect for individual agencies’ capabilities’.⁸⁷ Yet, as the conflict between the LHB and Scot-PEP suggests, tensions continued to persist into 1993.

It is clear from the above examples, concerning the use of preventative measures against HIV/AIDS in Edinburgh during the early 1990s, that many factors shaped

⁸⁴ *Ibid*, GD24, C6, D4, AIDS and Prostitution (Part 2), Letters, J. Baynhan to A. Darling, 10 February 1994 and W. Davidson to G. Bath, 15 December 1993.

⁸⁵ *Ibid*, C5, D3 (2.2.1) Regional AIDS Group Agenda and Minutes (Part 3), Letter G. Bath, S. Forbes and D. Taylor to All Members of the RAG and the LAF, n.d.

⁸⁶ *Ibid*, B4, Lothian Regional Council, *An HIV/AIDS Strategy for Lothian*, First Edition (Lothian Regional Council, 1 December 1992).

⁸⁷ *Ibid*, p. 41.

policy. While local epidemiology and research played an important role in influencing the HIV/AIDS policy formation process, by shaping perceptions about the heterosexual threat of HIV/AIDS and maintaining this as a policy issue in the public eye, this was only part of a bigger picture. Such a picture reveals the ways in which factors such as legal, financial and moral judgements played a role in policy decisions at the local level, particularly at the implementation stages of policy. Closer scrutiny of these processes has revealed the ways in which the desire to control disease, especially those measures exclusively involving sex industry workers, was often conflated with attempts to control certain types of sexual behaviour.

The question of whether heterosexual transmission of AIDS was a serious threat to society continued to be debated South of the border and in the USA. In addition to the Cox and Day Reports, Berridge claims that several arguments were put forward during the early 1990s in England and Wales, which began to question the threat of HIV from heterosexual transmission. One argument held that the threat of heterosexual transmission had been a conspiracy manufactured by homosexuals as a screen to cover their own promiscuous behaviour.⁸⁸ Others questioned the spread of AIDS in Africa and claimed that it was difficult to prove how many deaths had been caused by AIDS, as Africans suffered from other endemic diseases with similar symptoms.⁸⁹ In addition, at the end of 1989, a Labour peer had been told in a parliamentary written reply that only one heterosexual man was known to have contracted HIV as a result of normal sex.⁹⁰ Moreover, Berridge argues that scientific (both epidemiological and biomedical) arguments outside the UK reinforced the

⁸⁸ V. Berridge, *AIDS in the UK – The Making of Policy, 1981-1994* (Oxford, Oxford University Press, 1996), p. 238.

⁸⁹ *Ibid.*

⁹⁰ *Ibid.*, p. 239.

views of heterosexual spread of HIV as a myth. In the USA, for instance, epidemiological evidence was used to support the view that heterosexual spread would not happen beyond that of the female partners of men in the recognised risk groups, due to the difficulty of female to male transmission.⁹¹ Berridge goes on to suggest that these types of arguments formed part of an Anti-AIDS Alliance in the UK, which contributed towards the erosion of the liberal response to HIV/AIDS and a shift towards the downgrading of HIV/AIDS as a policy issue.⁹²

In contrast, as this case study of Edinburgh highlights, perceptions about heterosexual spread acted as a strong driving force in maintaining HIV/AIDS as a policy issue. Furthermore, Edinburgh was seen as unique, since a relatively large proportion of those heterosexuals infected were women, representing a total of 21% of the UK's known HIV-infected women.⁹³ The majority of these women had acquired the infection through intravenous drug misuse and some of them were involved in prostitution to feed their drug habit. These factors influenced the way in which Edinburgh envisaged the potential spread of HIV and the potential burden on services, especially in the event that more women than men became infected with AIDS. Women were considered not only as individuals but also as having multiple roles in society as wives, mothers and providers of health care, education and income. Their welfare was crucial to the family unit as a whole.⁹⁴

A Homosexual Disease

⁹¹ *Ibid.*

⁹² *Ibid.*

⁹³ NAS, HH61/1496/1, 'Draft – AIDS Task Force – Women's Issues in Scotland', November 1991.

⁹⁴ *Ibid.*

While the response to AIDS education was dominated by fears over the heterosexual spread of the disease during this time, there remained a recognised need to keep the gay community informed about the risks of HIV and AIDS. Some studies began to show that young gay men, especially those new to the gay scene in the 1990s, needed further advice and education on the risks of AIDS. Again, local epidemiological evidence and research studies appear to have informed health education measures targeted at the homosexual community. Epidemiology showed a rise in the numbers of cases of HIV infection acquired through homosexual contact. In 1992, figures showed an increase of 25% compared to the previous year.⁹⁵ The HIV/AIDS Team stressed that some upward trends in homosexual rates could be due to the fact that testing had become more readily available, but the Team were also apprehensive that, nationally, young homosexual men were no longer taking sufficient care in their sexual practices.⁹⁶

The LHB provided some funding to SAM and the Harm Reduction Team to develop and pilot a health-related advice project for younger gay men.⁹⁷ By 1993, the LHB began to show more concern about the incidence of HIV amongst homosexual men in the light of further medical evidence. The GUM Clinic had carried out an anonymous sero-prevalence study over a two-year period. In a sample of 836 homo/bisexual men, 54 were found to be positive. Of these, 67% did not know that they were sero-positive at first attendance and 41% of the HIV-positive men, who had been screened

⁹⁵ LHSA, EUL, B4, Lothian Health Board, *HIV/AIDS in Lothian: Building Together - Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending 31 March 1992), p. 4.

⁹⁶ *Ibid.*

⁹⁷ *Ibid*, p. 31.

anonymously, did not have an HIV test during their attendance and were possibly unaware of their HIV-positive status.⁹⁸

Other studies on the homosexual community also gave cause for concern. Research on sexual behaviour and the use of condoms by men attending gay bars and clubs in Glasgow and Edinburgh found that unprotected anal sex was still widely practised.⁹⁹ In addition, SAM's experience of working in the gay community found a high degree of complacency among a new generation of gay men who perceived HIV as 'an older person's problem'.¹⁰⁰ These findings contributed to the evolution of the Bar Jar Scheme operated jointly by SAM and the AIDS HRT.¹⁰¹ This scheme supplied educational materials about safe gay sex as well as free condoms and lubricating gels, which were placed in glass jars on bar counters.

SAM had started to shift its remit during this time in the face of changing perceptions of the risks of HIV/AIDS, and began to re-focus on educational measures outlining the risks of infection among young gay men. From 1983, it had been the first voluntary organisation in Edinburgh to provide information and advice to gay men. From 1985, it had expanded its services by providing information and advice to the drug-injecting community and to wider heterosexual audiences, including the prison service, about 'safe sex'. In 1988, SAM became involved in innovative AIDS educational work at Edinburgh's Saughton Prison, disseminating information,

⁹⁸ *Ibid*, B3, Lothian Health Board, *HIV/AIDS in Lothian: Changing Times and Shifting Targets - Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending 31 March 1993), p. 5.

⁹⁹ L. D. Gruer and L. Sembatya, 'Sexual Behaviour and Use of the Condom by Men Attending Gay Bars and Clubs in Glasgow and Edinburgh', *International Journal of STD and AIDS*, 4, 1993, pp. 95-8.

¹⁰⁰ LHSA, EUL, GD24, B3, Lothian Health Board, *AIDS in Lothian: Facing the Facts - Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending 31 March 1990), Appendix 2, p. 9.

¹⁰¹ *Ibid*, B14, Lothian Health Board, *Report on Bar Jar Evaluation* (LHB, Harm Reduction Team, 1993), p. 1.

offering support and assistance to sufferers and providing individual counselling sessions.¹⁰² On the basis of this initiative and its policy of non-segregation, Saughton Prison was awarded a Butler Award in recognition of its policy on HIV in prisons.¹⁰³

In 1993, SAM formed the Gay Men's Project, which was designed to use peer education initiatives, relying upon sexual networks to pass on information about safer sex.¹⁰⁴ As part of the project, a guide to safer sex was published for gay men entitled, 'Get Ready for Action', which highlighted the many ways to enjoy sex with your partner without taking risks.¹⁰⁵ However, the decision to re-focus upon gay men appears to have contributed to the acrimonious collapse of SAM in 1996. According to the former Chief Executive of SAM, this became a fundamental problem, leading to some members of SAM 'fighting for its soul', while others wanted to continuing targetting wider populations.¹⁰⁶ As Berridge has noted, the re-gaying of AIDS amongst voluntary groups elsewhere in the UK also occurred during this period and led to divisions within the gay community.¹⁰⁷ However, SAM were at the same time beginning to experience financial trouble, particularly a reduction in funds from the SHHD after 1990. The SHHD had been critical of some of the material SAM produced, namely a 'Dora and Dan' booklet that they regarded as sexually explicit.¹⁰⁸ However, the extent to which this played a role in the decision to cut back funding is unclear.

¹⁰² NAS, SOE12/520, Minute, C. M. Reeve to J. Douglas-Hamilton, 20 July 1988.

¹⁰³ 'The AIDS Pioneers – Saughton Leading the World', *Edinburgh Evening News*, 9 March 1990; 'Saughton Opens the Door to Sympathetic AIDS Care', *Glasgow Herald*, 13 February 1990.

¹⁰⁴ LHSA, EUL, GD22/17/76, See, SAM's Gay Men's Project profile inserted inside *Meridian*, 76, January 1996. See also *Gay Scotland*, 67, March/April 1993, p. 15.

¹⁰⁵ *Ibid.*, GD22/21/40, Booklet, 'Get Ready for Action' – A Gay Man's Guide to Safer Sex (Scottish AIDS Monitor Gay Men's Project), [n.d.].

¹⁰⁶ *Personal Communication* with former Chief Executive of SAM, 7 March 2005.

¹⁰⁷ Berridge, *AIDS in the UK*, pp. 266-75.

¹⁰⁸ NAS, HH61/1521 'Note of Meeting Between Representatives of SHHD Division VF and SAM held at SAM HQ, Edinburgh on 6 February 1990'.

From the evidence presented above it is clear that ongoing concerns about the heterosexual spread of HIV dominated the policy response in Edinburgh during the early 1990s and were central to sustaining a liberal response with regard to health education measures that embraced the concept of sex outside marriage and the use and supply of condoms. Edinburgh's fears of heterosexual spread were also echoed at the national level which contributed to the maintenance of AIDS as a policy issue, as witnessed in the formation of an ATF, chaired by Forsyth. As will be shown in the next Chapter, fears about heterosexual spread of HIV also dominated policy developments in the field of drug misuse and testing initiatives during the early 1990s.

CHAPTER 10 - THE EXPANSION OF DRUG MISUSE SERVICES AND SURVEILLANCE OF HIV - 1990-1994

This chapter explores how concerns about heterosexual spread in Edinburgh also informed measures relating to drug misuse, HIV testing and surveillance measures. With respect to drug misuse policy an examination is made of how the Community Drug Problem Service (CDPS) was successful in encouraging General Practitioners (GPs) in Edinburgh to take a more active role in the management and treatment of drug misusers. This model was often cited as an example for others to follow. The increased employment of methadone maintenance, both outside and inside prison, is discussed in relation to HIV control.

This chapter further focuses on the extension of surveillance measures and explores the ways in which testing and screening for HIV came to be increasingly valued as a means of prevention of AIDS in the 1990s, in the context of growing concerns over heterosexual spread in Scotland.

Expansion of Drug Misuse Services

Although developments in needle exchange had contributed to a reduction in the incidence of needle sharing in Edinburgh, concerns still existed over the links between HIV and drug misuse. This was more so as heterosexual spread was seen to be intimately linked with drug misuse in the City. In order to limit heterosexual spread from intravenous drug misusers, via prostitution or perceived chaotic lifestyles,

drug services expanded throughout the 1990s, reinforcing the liberal stance to combat AIDS.

Needle Exchange

Needle exchange services continued to grow in Edinburgh during the 1990s and had become a well-established part of the overall drug misuse service in the community. In 1992, the LHB's Harm Reduction Team moved to a central location, operating both during the day and the evening in order to become more accessible.¹ The Team ran a mobile needle exchange service across Edinburgh. In addition to GPs offering clean needles, a total of 25 pharmacies were participating in needle exchange schemes and a non-statutory group, the Leith Drug Prevention Group, had become involved in needle exchange.²

Developments in Edinburgh reflected the acceptance of the importance of needle and syringe exchange as a prevention strategy by the Scottish Office. In their AIDS Task Force (ATF) Report they recommended that Health Boards (HBs) should explore the need for further exchanges and stated that the Scottish Home and Health Department (SHHD) would give 'sympathetic and speedy attention to any applications submitted by health boards'.³

¹ LHSA [Lothian Health Services Archive], EUL [Edinburgh University Library], GD24, B19, HIV/AIDS Back Up Services Resource Folder, Lothian Health Board, *HIV/AIDS in Lothian – Building Together - A Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending March 1992), p. 12.

² *Ibid*, B3, Lothian Health Board, *HIV/AIDS in Lothian – Strategies for Survival – A Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending March 1994), p. 34.

³ Scottish Home and Health Department, *HIV and AIDS in Scotland – Prevention the Key - Report of Ministerial Task Force* (SHHD, March 1992), p. 38.

Short Stay Crisis Centre

In 1994, Scotland's first short-stay residential service for drug users opened.⁴ This offered drug management programmes that included stabilisation and detoxification. Up to 13 adults could be accommodated and parent-child facilities were included. Run by a non-statutory group known as the Links Project, funding came from the Lothian Health Board (LHB) and Lothian Regional Council (LRC) Social Work Department. This type of service had been recommended by the Advisory Council on the Misuse of Drugs (ACMD) in their 1989 Report, but due to LHB's financial crisis in 1990-1991, it had been put on hold.⁵

Developments at the CDPS

The work by Scottish Office departments and the staff of the CDPS in Edinburgh began to reap dividends from the early 1990s. In 1990, CDPS staff consisted of one full-time consultant psychiatrist, one part-time senior registrar, two clinical assistant doctors, five community psychiatric nurses, one clinical psychologist, two administrators and a social worker employed on a sessional basis.⁶ By 1992, this had almost doubled with an increase in referrals from GPs. An evaluation of the service by Judy Greenwood concluded that the reduction in injecting, HIV prevalence, drug related deaths and criminal behaviour could be attributed in part to the 'co-operation

⁴ LHSA, GD24, B3, Lothian Health Board, *HIV/AIDS in Lothian – Strategies for Survival- Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending March 1994), p. 34.

⁵ Department of Health and Social Security, *AIDS and Drug Misuse – Part 1 – Report by the Advisory Council on the Misuse of Drugs* (London, HMSO, 1988), p.59.

⁶ LHSA, EUL, GD24, B19, HIV/AIDS Back Up Services Resource Folder, Lothian Health Board, *AIDS in Lothian - Facing the Facts – Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending March 1990), pp. 12-3.

of GPs and CDPS in a shared care approach to problem drug users in Edinburgh'.⁷ The service had by this time extended to East and West Lothian and the original Edinburgh service moved to a more central location in order to make it more accessible.⁸

By 1993, a survey of GPs carried out by the newly-appointed GP facilitator within CDPS indicated that 73% of GPs would prescribe for drug misusers.⁹ This was compared with only 36% in 1988. In addition, a survey of GPs attitudes about the CDPS revealed that 69% were positive and only 11% were negative. In the same survey, 74% of GPs were currently prescribing for drug misuse and 88% had referred patients to the CDPS. 'They particularly appreciated the specialist back-up, the good communication and the ethos of the service of the CDPS.'¹⁰ At this time CDPS's clinical management consisted of an initial assessment from a Community Psychiatric Nurse (CPN), followed by a discussion of appropriate treatment with the GP. Treatment was initiated at the CDPS and continued for up to 3 weeks, in order to stabilise the drug misuser on oral methadone before the GP took over prescriptions.¹¹ Elsewhere in Scotland and the rest of the UK, GPs remained reluctant to treat drug misuse.¹² Furthermore, while the use of methadone increased dramatically in the UK over the course of the 1990s, the picture was not comprehensive, especially so in Scotland. A paper presented to a meeting of the SHHD Task Force, reported that:

⁷ *Ibid.*, C6, D1, (9.4.0), Letter, J. Greenwood to G. Bath, April 1992.

⁸ *Ibid.*

⁹ J. Greenwood, 'Shared Care with General Practitioners for Edinburgh Drug Users', Paper Presented at the VIth International Conference on the Reduction of Drug Related Harm, Florence, March 1995. For a full copy see www.drugtext.org/library/articles/96716.html.

¹⁰ *Ibid.*

¹¹ *Ibid.*

¹² House of Commons, Scottish Affairs Committee, *Drug Abuse in Scotland – First Report* (HMSO, London, 20 April 1994), p. xxi; Department of Health, *AIDS and Drug Misuse – Update – Report by the Advisory Council on the Misuse of Drugs* (London, Her Majesty's Stationery Office, 1993), p. 17.

The position in Glasgow has historically been rather different and with a very few exceptions, neither psychiatrists nor GPs have undertaken the prescription of methadone as a substitute. Even where there have been attempts to undertake prescription, these have not been coordinated as in Edinburgh, and there are no drug psychiatrist services in Glasgow.¹³

In his ATF Report, Forsyth stated that substitute prescribing had a place in prevention strategies against HIV and recommended that HBs should collaborate with statutory and voluntary organisations to review their HIV prevention measures in order to ensure that drug-related issues were adequately covered.¹⁴

Drugs Task Force

Similar views on substitute prescribing were reiterated in a Scottish Office Drugs Task Force (DTF) Report chaired by the Minister of State, Lord Fraser, in 1994.¹⁵ This Task Force had been formed to address the increase in drug misuse in Scotland over the previous ten years. Harm minimisation was given the official Seal of Approval. The Report stated that:

In the prevention and education fields, harm minimisation is a legitimate approach. This is not to condone drug taking but simply to acknowledge that it would be foolish to pretend that drug taking of this kind does not take place; and therefore the pragmatic response is to provide information and advice about minimising the risks.¹⁶

The Report also emphasised that harm minimisation should not exist in isolation from other services. It was recommended that the CPDS model be further developed with a

¹³ NAS [National Archives of Scotland], HH61/1496/1, Document, 'Draft Oral Methadone Substitute Prescribing for Drug Users Paper by Secretariat', September 1991.

¹⁴ Scottish Home and Health Department, *HIV and AIDS in Scotland – Prevention the Key - Report of Ministerial Task Force* (SHHD, March 1992), p. 40.

¹⁵ Scottish Home and Health Department, *Drugs in Scotland: Meeting the Challenge - Report of Ministerial Drugs Task Force* (SHHD, October 1994), p. viii.

¹⁶ *Ibid*, p.17.

view to receiving referrals from social work services and providing support to families of drug misusers.¹⁷ In addition, the DTF also noted that the Edinburgh CPDS had positively influenced the criminal behaviour of drug misusers and recommended that Glasgow carry out a similar study.¹⁸ On the role of GPs in the management of drug misuse, the Report recognised that further action to support them would be necessary at both local and national level.¹⁹

Methadone in Prison

By 1991, some aspects of Edinburgh's approach to drug misuse with respect to substitute prescription had been extended to Saughton Prison, with the help of the CDPS. Edinburgh's prison had long been a focus of concern with regard to the threat of heterosexual spread to the wider population. Its Governor, John Pearce, was a member of the Regional AIDS Group (RAG) and had established close links with other members from the statutory and non-statutory sectors of the AIDS-response community in Edinburgh, especially with respect to health education measures in Saughton.

A number of Edinburgh's criminals were sent to Saughton for drug misuse offences or related criminal acts of theft or prostitution, undertaken to fund their habit. It was believed that some prisoners continued to inject drugs in prison and have homosexual contact. As there was no access to clean needles or condoms in prison there was fear that their return to the community could provide a 'bridge' into the wider heterosexual

¹⁷ *Ibid*, p. 45.

¹⁸ *Ibid*, p. 85. Greater Glasgow Health Board had established its own Drug Problem Service in early 1994, drawing on practice in Lothian. See *Ibid*, p. 44.

¹⁹ *Ibid*, p. 48.

population.²⁰ The Saughton experience until 1990, like the whole of the Scottish Prison Service (SPS), had rejected the notion of issuing condoms and clean needles to prisoners and concentrated on education, information and counselling. The SPS rejected the issue of condoms in prison, since this would condone an illegal act, as homosexual practice was unlawful in a public place.²¹ Condoms were also seen as ideal receptacles for concealing drugs. The SPS also rejected the issue of injection equipment as it was felt that it would encourage drug misuse and undermine efforts to return inmates drug-free to the community.²² Needles were also considered to be dangerous because of their potential to be used as weapons. Instead, extra measures such as the introduction of closed circuit television and the use of sniffer dogs were used to reduce the opportunity for drug taking and homosexual acts.²³

However, the Scottish Office faced increasing criticism amid concerns that needle sharing was common in prisons. In addition, the number of inmates admitted to Scottish prisons, who had recently taken drugs was escalating.²⁴ Figures for 1989 also indicated that around 70 prisoners in Scottish prisons were HIV-positive, although the real level was thought to be higher.²⁵ Concerns about drug misuse in prison were also raised in the context of prison unrest at Glenochil Prison, a young offenders institution. A Ministerial meeting was held to discuss drugs and viral infection in prisons soon after these allegations.²⁶ Michael Forsyth was especially

²⁰ LHSA, EUL, GD24, C5, D3, Regional AIDS Group Agenda and Minutes, part 2, Document, 'AIDS in Prison - A Report by the Director of Social Work', 1988/89.

²¹ NAS, HH61/1515/1, Document, 'Drugs and AIDS/HIV Infections in Scottish Penal Establishments', April 1989.

²² *Ibid*, SOE12/520, Document, 'Briefing Material for Press Conference – AIDS and Prison', September 1988.

²³ *Ibid*, HH61/1515/1, Document, 'Drugs and AIDS/HIV Infections in Scottish Penal Establishments', April 1989.

²⁴ *Ibid*.

²⁵ *Ibid*, Draft, 'New Moves to Tackle AIDS and HIV in Jails', 12 July 1989.

²⁶ *Ibid*, 'Drugs and Viral Infections in Prisons – Ministerial Meeting on Thursday 27 October 1989'.

concerned by reports that a single needle had been passed around some prisons, one of which was in his constituency. He felt that the Government needed to be in a position to defend its argument that the problems of drug taking and homosexuality were controlled in prisons and suggested that research be undertaken to determine the extent to which allegations were true.²⁷

In response, the SPS created a Prison Service Working Group to review policies for the management of HIV infection and AIDS in Prisons. This led to a two-day conference at Saughton Prison in September 1990. The conference was attended by doctors, psychiatrists, social workers, academics, voluntary workers, prison staff and prisoners. Reporting on the Conference, *The Scotsman* announced that one study, by a specialist at Greater Glasgow HB, based on interviews with drug misusers about their experiences in prison, showed that 80% of drug users questioned in their survey knew of prisoners who were sharing needles.²⁸ A total of 64% of the sample admitted to taking drugs in prison, 25% said they had injected in prison and 11% said they had shared needles. The Scottish Office claimed their own research, based on interim findings with serving prisoners, suggested a lower incidence of needle sharing. For example, of a total of 559 inmates questioned, 17.3% claimed to have shared needles prior to imprisonment, but only 5.7% shared inside prison.²⁹

Following the conference and the attendant media coverage, civil servants within the Home side of the SHHD impressed upon their Ministers the need to agree to two pilot measures. The first was designed to carry out an anonymous HIV prison screening

²⁷ *Ibid.*

²⁸ B. Christie, 'Prison Drug-Use Study Finds Needle Sharing Rife', *The Scotsman*, 24 September 1990, p. 1.

²⁹ NAS, HH61/1254, 'Prison Service Conference on AIDS/HIV – HM Prison Saughton', 25/26 September 1990.

survey in order to gather information about needle sharing and enable prison management to plan facilities for infected and at risk individuals. It was anticipated that this would be carried out at Saughton Prison in the first instance. The second measure was to introduce a pilot drug maintenance/reduction programme at Saughton, that would allow for greater continuity of treatment and care for drug misusers admitted to prison and would have the reduction of needle sharing in prison as an objective.³⁰ It was noted that Edinburgh medical practitioners, including psychiatrists at the CDPS, were willing to help in this regard. The second measure had also been recommended by the ACMD in their Second Report as a means of reducing the sharing of needles.³¹

By 1991, an anonymous screening survey for HIV had been carried out at Saughton with the help of Dr Graham Bird, the Immunologist in charge of the HIV Immunology Unit at the University of Edinburgh. The findings from this study indicated that, out of 378 inmates who took part in the study, 18% were injecting drug misusers.³² Approximately half of these had injected while inside prison. These findings indicated that the HIV prevalence was 25% greater than the prison's medical service had been aware of and this evidence provided the impetus to proceed with the pilot study of a substitute prescribing reduction programme. The programme involved the prescription of methadone for a period of 28 days on a reducing basis, combined with counselling and education. The development was warmly

³⁰ *Ibid*, Draft Minute, J. W. H. Irvine to J. Douglas Hamilton, 10 October 1990.

³¹ Department of Health, *AIDS and Drug Misuse – Part 2 – Report by the Advisory Council on the Misuse of Drugs* (London, Her Majesty's Stationery Office, 1989), p. 65.

³² A. G. Bird, S. M. Gore, D. W. Jolliffe and S. M. Burns, 'Anonymous HIV Surveillance in Saughton Prison, Edinburgh', *AIDS*, 6:7, (1992), pp. 725-34.

commended in Forsyth's ATF Report.³³ By 1994, a similar approach had been adopted at Glenochil and Perth Prisons. The DTF Report also recommended that the SPS should develop this further.³⁴

The above evidence on the development of drug services in connection with the prevention of HIV/AIDS suggests that drug policy became more harm reductionist in its approach in the face of ongoing concerns about the heterosexual spread of HIV from Edinburgh's drug injecting population, including prisoners, who had also become vectors of disease. It was these concerns that were behind the changes in attitude towards drug misuse and informed subsequent policy documents on drug misuse in Scotland. Such a policy adopted a more liberal stance than its counterpart in England, regarded by Berridge as marking 'a revival of the hard-line response', where drug misusers were encouraged to use drug services that prioritised abstinence.³⁵

Surveillance of HIV

Antenatal HIV Screening

Just as the antenatal research project in Edinburgh was beginning to recover from the controversy surrounding its introduction in 1988 (see Chapter 7), another serious problem presented with the withdrawal of its funding. The MRC wrote informing the

³³ Scottish Home and Health Department, *HIV and AIDS in Scotland – Prevention the Key - Report of Ministerial Task Force* (SHHD, March 1992), p. 70.

³⁴ Scottish Home and Health Department, *Drugs in Scotland: Meeting the Challenge - Report of Ministerial Drugs Task Force* (SHHD, October 1994), p. 96.

³⁵ V. Berridge, *AIDS in the UK – The Making of Policy, 1991-1994* (Oxford, Oxford University Press, 1996), p. 287.

research team of its decision to cease funding beyond two years in 1990, having originally agreed to fund the project for three years.³⁶ A number of reasons were given for refusal to continue their support. The study had been planned before the introduction of unlinked anonymous testing for all women attending antenatal clinics, which was now available.³⁷ By 1990, anonymous screening was gradually being introduced in antenatal clinics, Genito-Urinary Medicine (GUM) clinics, drug dependency units, hospital patients and newborn infants around the UK.³⁸ In Scotland, although the SHHD believed anonymous testing to be of limited value, they had followed suit with the rest of the UK because surveys started to gather pace from the 1990. This included GUM clinics in Edinburgh and Glasgow and an MRC funded research studies on newborn infants.³⁹ As mentioned above, anonymous testing in prisons had also taken place.

A second reason for the MRC's refusal to continue funding the project was concern over the refusal rate, which would have an impact on conclusions drawn from its findings. The final reason given by the MRC was that the Royal College of Obstetrics and Gynaecology (RCOG) had started to recommend that all pregnant women at risk should be offered named, voluntary testing as part of normal clinical practice and that this should be supported financially by relevant HBs. Therefore it was argued that the study was no longer appropriate for MRC resources.⁴⁰

³⁶ LHSA, EUL, GD24, C6, D2, (13.1.0) – Ante-Natal Screening Project (part 2), Letter, A. C. Peatfield, MRC, to D. Reid, 23 July 1990.

³⁷ Berridge, *AIDS in the UK*, pp. 211-3.

³⁸ *Ibid.*

³⁹ NAS, HH61/1493/1, Draft Minute, J. T. Brown to Minister of State, May 1991.

⁴⁰ *Ibid.*

The news was met with great disappointment by LHB staff and also some members of parliament, particularly the Labour MP for East Edinburgh, Gavin Strang, who wrote to the Scottish Health Secretary expressing his concern. The response to Strang was a reiteration of what the MRC had said to its grantholders. However, the SHHD advised Scottish Office ministers that it would be premature to curtail the study at this stage, particularly when it was about to draw on data which would be used to estimate the extent of heterosexual spread in Edinburgh and Dundee.⁴¹ It was argued that some women who took part were consequently identified as HIV positive and may have been missed because they were in a perceived low risk category. The anonymous unlinked study would not provide this type of information. Nor would it provide answers on how people became infected. For these reasons the SHHD convinced ministers to provide funding for a further 3 months up to the end of 1990.⁴² Although the study had finished, women in Edinburgh who wished to obtain voluntary and attributable antenatal screening could continue do so through their clinic.⁴³

AIDS Prevention Co-ordinating Group (APCG)

While the Scottish Office were not prepared to carry on funding the above project, they did see the need to encourage wider antenatal screening measures, on a voluntary named basis, throughout Scotland. By 1993 new guidelines on offering voluntary, named HIV antibody testing to women receiving antenatal care had been created by the newly formed APCG, which was set up at the end of 1992, on the

⁴¹ NAS, HH97/85, Draft Letter, M. Forsyth to G. Strang, October 1990.

⁴² *Ibid*, Draft Minute, J. T. Brown to M. Forsyth, October 1990.

⁴³ LHSA, EUL, GD24, B3, Lothian Health Board, *Planning for the Future – HIV /AIDS in Lothian*, - *Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending 31 March 1991), p. 11.

recommendation of the ATF, to facilitate service co-ordination at the national level.⁴⁴

The group was chaired by a senior SHHD official and included health board, local authority, voluntary sector, Health Education Board for Scotland (HEBS), police and prison service representation. The APCG was asked to consider issues in the field of HIV and AIDS prevention. George Bath continued to represent the LHB, making him one of the few Edinburgh doctors to have been represented in every SHHD AIDS-related Working Group up to this time. In many ways the APCG was a bigger version of Edinburgh's RAG, which had been created in order to facilitate co-ordination at the local level.

The APCG guidelines on antenatal testing concluded that:

Board and Trusts are encouraged to introduce, where appropriate and as resources permit, a policy of offering named voluntary testing to all women attending antenatal clinics.⁴⁵

The guidelines also noted that such encouragement was justified in Scotland's case because recent studies on heterosexual transmission in Edinburgh and Dundee had indicated that, even women in low risk categories, were not immune to HIV infection and could also spread the disease to their children or heterosexually. It was argued that the benefits of voluntary, named antenatal testing would allow a woman to make an informed choice about her pregnancy at an early stage. This would include future care and whether or not to breastfeed. With regard to termination if a woman raised

⁴⁴ *Ibid*, p. 4. See also, *Ibid*, C1, D3, 'AIDS Prevention Co-ordinating Group for Scotland' – Minutes of First Meeting on 6 November 1992.

⁴⁵ *Ibid*, B5-6, Scottish Home and Health Department 'MEL(1993):154 Guidelines – Offering Voluntary Named HIV Antibody Testing to Women Receiving Antenatal Care – Appendix A', 10 December 1993.

the question, then this was to be dealt with in the usual manner, under the terms of the Abortion Act 1967.

Other benefits of voluntary named antenatal testing were early specialist referral for treatment against opportunistic infection or the use antiretroviral drugs to delay progression of disease, and advice on protection from sexually transmitted diseases (STDs) during pregnancy.

By this time, the evidence that Brette and others used to support the advice they gave to antenatal women in 1985 had changed. New evidence showed that while all babies born to HIV-positive women carried the maternal antibody, this tended to be for 6-10 months, after which time only 15-20% of babies developed their own antibodies to HIV.⁴⁶ In addition, new diagnostic procedures enabled infected babies to be identified earlier and the introduction of prophylactic therapies could delay life threatening opportunistic infections.⁴⁷

As Armstrong and others have argued, these shifts in wider surveillance measures for women can be seen as part of broader developments within public health medicine, such as mass immunisations programmes, whereby normal health becomes medicalised and subject to scrutiny.⁴⁸

Changing Emphasis on Testing and Screening

⁴⁶ *Ibid*, p. 3

⁴⁷ *Ibid*.

⁴⁸ D. Armstrong, 'The Rise of Surveillance Medicine', *Sociology of Health & Illness*, 17:3 (1995), pp. 393-404; Berridge, *AIDS in the UK*, p. 214.

In addition to encouraging antenatal HIV screening for all women in Scotland, the ATF recommended that more testing facilities should be available for the wider population. In 1992, the ATF Report discussed the costs and benefits of HIV testing. The Report stated that:

The increased availability and accessibility of testing which is both voluntary and attributable, accompanied by high quality pre-test and post-test counselling, should be encouraged.⁴⁹

Amongst the main arguments behind this recommendation was that those found to be HIV positive could benefit from the prospect of drug therapy, that a disclosed positive test could modify the behaviour of individuals and that information would enable government to target future health education initiatives.

New Testing Initiatives

In particular, the ATF recommended that two new initiatives in Edinburgh and Glasgow should be created in order to offer rapid testing. It was believed that some people failed to seek a routine test since the length of time before the result was known did little to alleviate initial anxieties.⁵⁰ The first initiative would be to establish accelerated testing facilities that would, if appropriate, provide results and counselling within 24 hours of the test being carried out. The second initiative would be to enhance testing services with longer opening hours. Efforts would be made to attract local people for testing via publicity. The Report stated that resources from the

⁴⁹ Scottish Home and Health Department, *HIV and AIDS in Scotland – Prevention the Key - Report of Ministerial Task Force* (SHHD, March 1992), p. 47.

⁵⁰ *Ibid.*

SHHD would be made available and if successful, such facilities would be introduced elsewhere in Scotland.

Edinburgh's New Testing Initiatives

In its 1993 Annual AIDS Report, the LHB announced that Lothian had participated fully in the work of the ATF, and had implemented accelerated testing schemes at the GUM Department at the Royal Infirmary and at the HIV Counselling Clinic at the City Hospital in response to recommendations.⁵¹ By 1994, money from the ATF enabled the LHB to set up testing clinics in the evenings and on Saturdays.⁵² For those considered to be in a low risk category for AIDS, the emphasis now placed on screening must have convinced some of the need for testing.

Contact Tracing (Partner Notification)

In addition to the encouragement of increased testing, the issue of contact tracing (or partner notification) was also placed on the agenda for the first time in Scotland, in connection with HIV.⁵³ Contact tracing had been practised in the context of other sexually transmitted diseases. However, as noted in Chapter 2, the Scottish experience had been one of variable practice and a lack of resources, due in part to concerns about civil liberties and the potential legal implications.

⁵¹ LHSA, EUL, GD24, B3, Lothian Health Board, *HIV/AIDS in Lothian: Changing Times and Shifting Targets, - Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending 31 March 1993), p. 19.

⁵² *Ibid*, Lothian Health Board, *HIV/AIDS in Lothian: Strategies for Survival - Report in Response to the AIDS (Control) Act 1987* (LHB, Year Ending 31 March 1994), p. 22.

⁵³ Scottish Home and Health Department, *HIV and AIDS in Scotland – Prevention the Key - Report of Ministerial Task Force*, (SHHD, March 1992), pp. 48-9.

The Scottish ATF thought the evaluation of contact tracing in the context of HIV was complex, because of the lack of a cure for the condition, a fear that contacts might become ineligible for life insurance if tested, and the delay between initial infection and the presentation of symptoms.⁵⁴ At the same time, the Expert Advisory Group on AIDS (EAGA) was discussing the issue at the national level and the ATF did not want to pre-empt their work. A decision was made to await the outcome of EAGA's considerations. In the meantime, it was recommended that arguments for and against tracing contacts should be covered in routine pre and post-test counselling. The ATF also took the view that in the event that an individual wishing Health Service staff to alert contacts, this should be done sensitively.

Contact Tracing in Edinburgh

The lack of a firm Scottish Office directive on contact tracing was felt to be a missed opportunity by some in Edinburgh, who considered that there was a strong case for a policy on the issue. Bird argued that Edinburgh's situation was unique, in that infection could spread efficiently because of the large numbers of intravenous drug misusers, whose high rate of incidence of HIV would be enough to keep an epidemic going. He argued that contact tracing was necessary to 'interfere with the chain of transmission' even if there were no identified effective treatments for the condition.⁵⁵ Roy Robertson, (generally associated with liberal measures in response to AIDS such as needle exchange and methadone substitution) was also in favour of contact tracing and was carrying out the practice in his surgery. From his point of view, a government-supported initiative was more urgent in Edinburgh because of the type of

⁵⁴ *Ibid.*

⁵⁵ BBC Scotland, Focal Point, *Killing without a Trace*, 15 October 1992.

population involved and the consequences of increasing heterosexual spread to non-drug misusers.⁵⁶ Informing some of the arguments in favour of contact tracing in Edinburgh, were concerns that some women who were partners of drug misusers were particularly vulnerable as they were in abusive relationships that left them with little control over protection.

In this context, the issue of individual civil rights versus the needs of society is clearly prominent. In the discussion, some doctors and commentators were strongly against the idea of any form of contact tracing on the grounds that civil liberties would be infringed. Dr Gordon Scott, Consultant in GUM at Edinburgh, warned that the major worry would be that a policy of compulsion would have negative consequences, with individuals failing to attend GUM clinics in the first place if they feared they had to name names.⁵⁷ He argued that there had to be a clear benefit to the individual, such as a cure, before firm steps could be taken to encourage patients to pass on confidential information. Derek Ogg of Scottish AIDS Monitor (SAM) was also strongly against any form of contact tracing because of the issue of civil liberties. He felt that this type of policy would be nothing more than a policy of 'tracing criminals', whether they were drug misusers, consenting homosexuals who were under the age of 21, or prostitutes. He argued that individuals needed reassurance about confidentiality, not a health system where they were 'nagged, tagged and bagged' like rabbits with myxomatosis.⁵⁸

National Guidelines on Contact Tracing

⁵⁶ *Ibid.*

⁵⁷ *Ibid.*

⁵⁸ *Ibid.*

Clearly, the issue provoked mixed feelings in Edinburgh and elsewhere. Similar arguments were being addressed south of the Border in response to a widely publicised case of a haemophiliac man who had infected his son and a number of girlfriends.⁵⁹ This contributed to the production of guidelines in 1992, advocating contact tracing.⁶⁰ By 1993, Scotland had produced similar guidelines. The Scottish guidelines were offered to assist health care professionals in HBs and Trusts in the development of local strategies aimed at identifying partners of people infected with HIV.⁶¹ The guidelines also stated that due to the advent of therapies, which might delay the progression to disease in HIV infection, and changes in the nature of the epidemic, (particularly the spread to heterosexuals in low prevalence areas), the development of partner notification was important.⁶²

From the evidence presented above on the shifts in drug misuse policy, it has been shown how continuing concerns about a potential heterosexual spread, especially from prisoners, led to an increasingly liberal approach to drug misuse in Scotland by 1994. Harm minimisation had become reluctantly accepted by the Scottish Office as a legitimate means by which to address not only the spread of HIV, but, as the Edinburgh CDPS evidence had shown, as a means of reducing crime. At the same time, although new drug therapies changed the emphasis on the need for increased screening measures, fears about heterosexual spread also fed into debates around increased screening measures for antenatal women and contact tracing measures. The

⁵⁹ Berridge, *AIDS in the UK*, p. 256.

⁶⁰ *Ibid.* See also, Department of Health, PL/CO (92)5 *Guidance of Partner Notification in HIV Infection*, Appendix 3, December 1992.

⁶¹ LHSa, EUL, GD24, B5-6, Scottish Home and Health Department 'MEL(1993):154 Guidance on Partner Notification for HIV Infection – Appendix B', 10 December 1993, p. 1.

⁶² *Ibid.*

attention to pregnant women widened, to include all of those in Scotland, as they continued to be singled out for testing, making them targets for medical surveillance.

CHAPTER 11 – CONCLUSION

This chapter forms the conclusion to this thesis and contains three sections. The first section compares and contrasts the stadial model of AIDS policy-making in UK with the Edinburgh response to AIDS. Section Two locates some of the main themes identified in this thesis within the context of the historiography of the social response to disease. The final section is a coda, which highlights further areas for research on the history of AIDS policy-making in Edinburgh.

Berridge's Stadial Model of AIDS Policy-Making in the UK – 1981-1994 Re-Visited

One of the central aims of this thesis has been to compare and contrast the State's response to AIDS north of the Border with the stadial model of the history of AIDS policy-making in the UK, between 1981-1994, as put forward by Virginia Berridge.¹ Particular attention has been given to differences between both the type and timing of the policy responses in the UK and that pursued in Edinburgh. By comparing these differences, it will be shown that many were the result of local factors, such as the particularities of local epidemiology, revealed by research on AIDS and HIV, the legacy of previous responses to disease, and the particular configuration of local pressure groups and civic authority. Differences can also be explained by a number of distinctively Scottish factors, including Scotland's own government departments, legal system, churches, health education structures and Blood Transfusion Service (BTS).

¹ V. Berridge, *AIDS in the UK – The Making of Policy, 1981-1994* (Oxford, Oxford University Press, 1996).

Phase One (1981 – 1985)

Phase One of Berridge's stadial model is described as a period of 'Policy from Below'.² This phase is characterised by policy formation at the local level, through gay groups, and medical and scientific groups, many of whom forged alliances and developed a policy community around AIDS. From 1981, gay men began to spread the news about the incidence of AIDS in the USA. The first official gay voluntary organisation, the Terrence Higgins Trust (THT), was formed in London in 1982 after his death from AIDS. Scientific groups, from fields such as immunology and virology, became another policy lobby. This was also a time when medical specialties such as Genito-Urinary Medicine (GUM) came in from the cold, by virtue of AIDS, having previously been regarded by some as a 'Cinderella speciality' with poor facilities.³ Noticeable within the policy community was their ability to make AIDS a high profile media issue in order to press the Government for urgent action.

The UK Government began to respond to AIDS in 1983. Donald Acheson, the Chief Medical Officer (CMO) of the Department of Health and Social Security (DHSS), began to hold meetings with members of the AIDS policy community. At this time, there was a lack of government consensus in favour of a liberal response to AIDS. Some politicians argued for AIDS to become a notifiable disease. However, by 1985, a liberal response was beginning to emerge. Calls for notification were rejected in favour of a response that focused on individual rights and responsibilities and was defined by traditional forms of health policy-making, which relied on the expertise of

² *Ibid*, pp. 13-78.

³ *Ibid*, p. 25.

the medical and scientific professions. Crucial in this respect was the work of Acheson and the newly-formed Expert Advisory Group on AIDS (EAGA), which he created in early 1985, in order to advise the Government. The EAGA was made up of members of the medical and scientific communities. At the end of 1985, Norman Fowler, the Health Minister, announced measures to combat AIDS costing at circa £6.3 million (£2.5 million of which was set aside for a national information campaign), clearly indicating that, by this time, AIDS had risen to some prominence in the political agenda.

In Edinburgh, the response to AIDS followed a similar trajectory to that of Berridge's model. The policy community there was equally active in raising awareness of AIDS and bringing it to the attention of the Scottish Office. However, there were a number of differences within this phase, with respect both to the timing and type of policy response. It would appear that Edinburgh's policy community emerged at a slightly later period than London. In 1982, Dr Sandy McMillan began to spread information about the risks associated with AIDS, around gay venues in Edinburgh. Around the same time, the gay community began to warn of the dangers of having sex with gay American men. Similarly, the first voluntary AIDS group in Edinburgh, the Scottish AIDS Monitor (SAM), formed a year after the THT. In addition, and in contrast to the THT, SAM arose out of concerns over the need to secure safe blood supplies, having formed an early alliance with the local medical community in 1983.

Differences in the type and timing of policy initiative can also be identified with respect to changes in blood donation policy, which occurred in Edinburgh. In this thesis, I have argued that Edinburgh's past legacy of disease experience, especially

the lives lost through the outbreak of Hepatitis B a decade earlier, may have contributed to early action by heightening local sensitivities. In addition, further changes in blood donation policy, ahead of the UK, were made at the national level by the Scottish BTS to secure blood supplies. These measures appear to have been associated with concerns over the potential damage to Scotland's recent achievement of self-sufficiency of blood supplies.

Edinburgh also showed variance from Berridge's model in terms of medical input to policy-making. In particular, the Infectious Disease (ID) specialty, whose status had declined over previous decades, was to play a prominent role. The evidence, emerging around mid 1985, of the high incidence of HIV through intravenous drug misuse, rather than sexual transmission, appeared to bolster the case for this specialty to be better recognised and resourced. In October 1985 an 'open access' clinic, created by Dr Ray Brett, was established to provide screening and counselling for the many drug misusers who attended his department.

When we consider the input of government during this period, we can note that in some aspects, the Scottish Home and Health Department (SHHD) diverged from their counterparts south of the Border, especially with respect to the issue of disclosure. Scottish policy on the disclosure of medical information about HIV amongst haemophiliac children, led to differences in guidelines for educational establishments and was subsequently applied to prisons and social work departments in Scotland. As noted in Chapter 4, this decision appears to have been influenced by the medical profession, including some local doctors, who stressed the importance of patient confidentiality in order to avoid stigmatisation. Subsequently, despite the views of

the Scottish Health Minister, John MacKay and the Scottish Education Department (SED), both of whom favoured more disclosure, as in England and Wales, the SHHD were not prepared to follow suit.

Phase Two (1986 - 1987)

Phase Two of Berridge's model is described as the period of the 'Wartime Response' to AIDS.⁴ At this time AIDS was seen as a political priority requiring a high level of government intervention. The perception of the disease, and its threat to attain epidemic proportions, was seen to merit action on a scale akin to the Second World War. The 'Wartime Response' was evident by October 1986 in the formation of an Interdepartmental Ministerial Cabinet Committee on AIDS, chaired by the Deputy Prime Minister, William Whitelaw. The perception of crisis was also confirmed in November 1986 by a full-scale House of Commons Debate on AIDS, chaired by Norman Fowler, who stressed the need for cross-party consensus. By the end of 1986, a public education campaign in the form of advertisements in the national press had been completed and this was expanded with the announcement that £20 million would be made available for a campaign to include television and newspaper advertisements and the distribution of a leaflet to all households in the UK. The overall reaction represented a liberal consensual approach to AIDS prevention, stressing the importance of safe sex and harm minimisation rather than the espousal of a moral agenda advocating no sex and no drugs.

⁴ *Ibid*, pp. 81-152.

At the same time the Health Education Council (HEC) was replaced by a new Health Education Authority (HEA) which was more directly answerable to Westminster. This was part of a bureaucratic strategy to provide a 'respectable out' for Ministers, concerned about their involvement in controversial issues whilst at the same time wanting to influence policy. Therefore, in this respect, the response to AIDS was neither a 'New Right' nor a traditional policy-making reaction.

This phase also included the formation, in 1987, of a Social Services Committee on the *Problems Associated with AIDS*, which also confirmed a liberal line, particularly with respect to arguments against widescale HIV screening. Amongst the factors that shaped the political response to AIDS at this time, were concerns about heterosexual spread, as already brought to the fore in Edinburgh, the work of the policy community in raising the issue to the political level, the work of government departments through the role of civil servants and personalities such as Acheson, and the role of the media.

In Edinburgh, the path of policy initiative during this time was broadly similar to that of the UK model. Local authorities began to respond in a joint effort to tackle Edinburgh's potential crisis and the policy community was instrumental in raising the issue of AIDS and drug misuse with the SHHD, which led to the formation of the McClelland and Tayler Committees. However, despite the prominence of Edinburgh's high rate of infectivity in contributing to the 'Wartime Response' at the Westminster level, there were still a number of differences. For example, as noted in Chapters 5 and 6, the continued reluctance of the Scottish Office to respond to some aspects of AIDS policy was apparent in the lack of importance attached to mass media

campaigns during 1986 and 1987. MacKay in particular was concerned about the explicit nature of the 1987 campaign material.

Indeed at the level of political personalities, MacKay and his counterpart south of the Border, Fowler, were opposites in their response to AIDS. Fowler's liberalism stood in contrast to MacKay's illiberalism. Compared With Margaret Thatcher's title for Fowler as Minister for AIDS, MacKay might be described as the Minister for Morality.⁵ He used the media to undermine the McClelland Report of 1986, believing that AIDS was a straightforward moral issue that did not deserve extra government funding to introduce safe sex messages or harm minimisation measures.

Differences in policy response were also apparent with respect to the introduction of needle exchange schemes throughout the UK. Scottish schemes were funded for a shorter time, they were hospital based, medically supervised, and, in the case of Edinburgh, limited by the frequency of opening hours and the number of needles and syringes issued per visit. While this difference was shaped by political reluctance, there was also resistance to needle exchange from the SHHD and from the local medical profession. At the SHHD, although some civil servants such as Robert Covell, the ID representative, were in favour of needle exchange from the public health perspective, the issue was complex due to moral, financial and legal constraints. In the Edinburgh context, as was noted in Chapter 6, with the exception of a few, there was great reluctance to participate amongst General Practitioners (GPs), who saw the schemes as unscientific and perceived drug misusers to be disruptive. These factors all contributed to the somewhat paradoxical situation

⁵ *Ibid*, p. 102.

whereby Edinburgh's official needle exchange was the least liberal of exchanges throughout the UK.

In the context of methadone prescription, this also resulted in a different policy response in Edinburgh; one that witnessed the ID specialist, Brettle, being asked to prescribe methadone to HIV-positive intravenous drug misusers only. While there was reluctance on the part of the SHHD to address the issue of substitute therapy, this thesis has argued that the reluctance of psychiatrists to become involved in the management of drug misuse played a part in the steps taken by Brettle. As shown in Chapter 2, this reluctance dated back to the 1960s when psychiatrists were invited to take an active role in the field of substance abuse.

Phase Three (1987 - 1989)

Phase Three of the AIDS policy response moved into a period termed by Berridge as 'Normalisation and Chronic Disease'.⁶ The 'Wartime Response' had waned with the departure of Fowler in 1988 and the near simultaneous retirement of William Whitelaw. An AIDS Minister was not appointed and the AIDS Ministerial Cabinet Committee disbanded in 1989. The Report of the Advisory Council on the Misuse of Drugs (ACMD) on *AIDS and Drug Misuse* was finally published in March 1988, having been presented to Ministers some six months earlier, but delayed because it contained recommendations for an expansion of harm minimisation measures.

⁶ *Ibid*, pp. 155-227.

This phase also witnessed a shift in definition of AIDS from an 'epidemic' disease to a 'chronic' disease, powerfully influenced by epidemiology, which suggested that the rate of growth of the incidence of the disease had slowed. The definition of AIDS was also re-shaped by the development of treatments, such as AZT (Azidothymidine/Zidovudine), which could influence the severity and course of the condition. AIDS came to be perceived as a 'normal' disease like many other chronic conditions of the late twentieth century. This shift in definition coincided with a move away from the liberal consensus, and greater emphasis was placed on screening and testing, especially anonymous testing. Also, within this phase, input from within the voluntary sector underwent a qualitative change as voluntary initiatives and agencies were increasingly undermined by paid professionalism within highly organised and better-funded bodies.

This thesis has shown that the Edinburgh response matches Phase Three of Berridge's stadial model in some respects, especially the emphasis on screening and testing and changes to the voluntary sector. At the level of Scottish Office, the 1987 general election had resulted in a new Scottish Health Minister, Michael Forsyth. Forsyth was more 'hands-on' than MacKay and appeared to be determined to make every effort to ensure that the Scottish Health Department followed its UK counterpart. He endorsed the recommendations in the Tayler Report and agreed to fund three Special AIDS Units for patients, in line with those developed in London, and introduced new testing initiatives for women similar to those in some parts of the UK.

Forsyth was equally concerned that Scottish views were represented in national policy-making decisions. He sanctioned the UK-wide Anti-AIDS, shock-horror mass

media campaign at the expense of the Scottish Health Education Group (SHEG)'s anti-drug campaign, which had been based on a health education approach, emphasising the positive aspects of a drug-free lifestyle.

However, differences have also been identified in the type of response in other areas, which resulted in the 'Wartime Response' retaining a prominent place in the Edinburgh reaction, as policy became more liberal by the end of this phase, especially with respect to harm minimisation and safe sex messages. A number of factors appear to have shaped this reaction. In 1988, the Scottish Office faced severe criticism from the ACMD over its response to AIDS and drug misuse and this appears to have prompted policy changes and reflected a shift in attitude about the need to seriously address the issue of HIV and AIDS. Further attempts were made to encourage psychiatrists and GPs to take a more active role in drug misuse. Scottish Office funding was made available to develop a Community Drug Problem Service (CDPS) in Edinburgh by Dr Judy Greenwood and needle exchange schemes were expanded.

The shift in definition of AIDS to a 'chronic' disease in Edinburgh is also less clear during this phase. For example, Edinburgh's high rate of HIV infectivity amongst drug misusers, many of whom were young and sexually active heterosexuals, remained a source of concern for Edinburgh policy makers. The power of local epidemiological studies, as conducted by Dr George Bath, and local research by Dr Roy Robertson and Brettle pointed to an 'epidemic' of heterosexual AIDS, at a time when predictions in the rest of the UK suggested the opposite. This appears to have contributed to a highly publicised local campaign, which emphasised safe sex, and

included free condoms during a period when, as documented in Chapter 8, the changing perception of AIDS in the rest of the UK contributed to the decision to cancel an advertising campaign on the use of condoms.

Phase Four (1990 – 1994)

The final phase of the response to AIDS in Berridge's stadial model occurred between 1990 and 1994 and is described as the period of 'the Repoliticization of AIDS'.⁷ A feature of this Phase was the continuing erosion of the liberal consensus, at both the political and scientific level. This was increasingly replaced with a policy response that continued to emphasise screening and surveillance and the rights of the public over individuals. At the same time, AIDS was being downgraded as a policy issue. By 1991, Donald Acheson, the Chief Medical Officer (CMO) had retired to be replaced by the former Scottish CMO who was more 'hands-off' with respect to the everyday issues around AIDS. Funding for AIDS continued to decrease and by 1993 the Department of Health's AIDS Unit had been incorporated into a general communicable disease unit. The abolition of funding for parts of the voluntary sector involved in drug-related issues also occurred.

Also, at this time, the gay community began to fragment. Some gay groups re-introduced the connections between AIDS and homosexuality. Other gay groups went beyond AIDS and focussed on wider issues such as sexual health. In addition, this phase was marked by a new 'anti-AIDS alliance' that used epidemiological and

⁷ *Ibid*, pp 231-79.

biomedical evidence to generate opposition to the view that AIDS was a major threat to the heterosexual population.

From the many areas of policy response a 'post war' pattern emerged, which incorporated pre-war and wartime tendencies, such as the changing role of the voluntarism and the state, revealing elements of continuity and change. Furthermore, a liberal response was maintained in some areas, particularly with respect to changes in prison policy. By the early 1990s, AIDS was simultaneously mainstreamed and marginalized.

As with the other phases of Berridge's model, similarities can be identified between Edinburgh and the UK model, especially with respect to greater emphasis on screening and testing, reduction in government funding in some areas, such as the voluntary sector, and the fragmentation of some of the original voluntary groups. However, as shown in this thesis, the ongoing concerns about a potential heterosexual epidemic contributed to maintaining AIDS as a 'Wartime' issue in Scotland in many respects. National and local epidemiological evidence helped maintain this view. Indeed, members of the original Edinburgh policy community, such as Bath and Robertson, were influential in sustaining awareness of a threat of a heterosexual epidemic during this phase, with their input locally and nationally. Added to this, new research into the behaviour of prostitutes and prisoners concluded that many were continuing to take risks. The policy response became increasingly liberal with regard to health education and drug misuse management, some of which was funded directly by the Scottish Office. In addition, the SHHD increased the Lothian Health Board (LHB)'s funding during 1991-1992 for AIDS/HIV and drug misuse services,

which helped boost the 'Take Care' campaign, funded health education initiatives targeted at prostitutes and contributed to the establishments of a new Short Stay Drug Crisis Centre. Furthermore, the Infectious Diseases Unit continued to prosper with respect to funding and status with the opening of the Special AIDS Unit in Edinburgh in 1991. In 1994, the 'Take Care' campaign had been extended again, with greater emphasis on empowering women.

Drug policy had also changed in the face of AIDS, with the legitimisation of harm minimisation as a measure to control HIV and treat drug misuse. GPs, through the hard work and encouragement of Judy Greenwood, started to accept a role in the management of drug misuse. Such was the success of the Edinburgh response to AIDS and drug misuse that these measures were adopted in other parts of Scotland, including some Scottish prisons.

As a result of ongoing concerns about the threat of heterosexual spread, AIDS remained a political issue with the creation of a new Ministerial AIDS Task Force in July 1991, chaired by Forsyth, who believed the battle against HIV had yet to be conquered in Scotland. On his recommendation, an AIDS Prevention Co-ordinating Group was set up in 1992 in order to facilitate co-ordination at a national level, under the chairmanship of a senior SHHD official. The strong emphasis on prevention, reflected concerns about heterosexual spread of HIV.

Berridge's stadial model has provided a historical lens through which to analyse the AIDS policy-making process in the UK. It has demonstrated that the use of historical concepts, which analyse change over time, can provide added insights into the many

complex layers of the policy-making process, confirming that AIDS policy was seldom a straightforward ‘New Right’ reaction nor a traditional health policy-making approach, legitimated by scientific and medical expertise. The findings in this thesis have provided additional insights into the ways in which local and Scottish factors shape policy, some of which are discussed below.

Themes Emerging from the History of the Policy Response to AIDS in Edinburgh – 1982-1994

The second aim of this thesis has been to provide an in-depth historical account of the Edinburgh response to AIDS, 1982-1994, in order to highlight the wider issues brought to bear upon the formation of health policy at the local level. In doing so, a number of important themes have emerged which deserve added attention. This is particularly so within the context of the historiography of the social response to disease, where one of the central weaknesses identified in the existing literature on the response to AIDS policy, as outlined in Chapter 1, is the lack of local policy responses in the UK.

The Role of the Local Medical Profession

Firstly, a common theme running through all stages of the AIDS policy-making process in Edinburgh, has been the influential role of members of the local medical profession in raising AIDS as a policy issue and also in defining policy, both locally and nationally. The arguments of Edinburgh’s scientific and medical community informed and shaped government AIDS policy. Members of the original medical policy community, such as McClelland, Brettell, Bath and Robertson stand out as key

players throughout the entire period, for their contributions, which kept AIDS in the limelight, both in the media, and at UK and Scottish Office government policy-making levels. Through their participation in government committees and research, their views fed into debates such as those over needle exchange, substitute therapy and the screening of antenatal women.

All of these factors confirm that Scottish AIDS policy in this respect was far from a 'New Right' reaction. While other groups, such as civil servants, health educationalists and voluntary workers played a role in influencing policy, in many areas of the policy response, local medical and scientific opinion prevailed, particularly in areas which were most contentious, such as needle exchange. In addition, the Edinburgh medical community, particularly Greenwood, succeeded in changing the way in which drug misuse was to be managed, despite fierce resistance against involvement from many local doctors. These findings form part of other histories of the social response to disease, which show that as far back as the nineteenth century, medical practitioners have played an influential role in policy-making process.

This study has also revealed insights into the way in which some medical specialities gained a new lease of life during this period of the response to AIDS in Edinburgh. Of particular note were Public Health, Genito-Urinary Medicine (GUM) and Infectious Disease. However, as argued in this thesis, it was the Infectious Disease specialty that appeared to have gained the most from increased status and funding.

The role of the medical profession in response to AIDS has also brought to light competing interests between medical specialties. For example, as was shown in Chapter 4, at the early stages of the response, the Head of GUM was concerned about the creation of an ‘open access’ clinic at the Infectious Diseases Unit. This thesis has also shown that even within specialities, such as Obstetrics and Gynaecology, differences over the ethical implications of screening women for HIV occurred, creating tensions.

The medical response to AIDS in Edinburgh has also been part of a larger story in the history of the NHS in late twentieth-century Scotland. For example, as was highlighted in Chapter 7, AIDS occurred at a time of great change in the NHS with the introduction of a new management structure in the mid-1980s, contributing to delays in the establishment of the Special AIDS Unit in Edinburgh. Chapter 9 also highlighted periods of financial difficulties for the LHB, which were part of further changes in the NHS, required before the implementation of *Working for Patients* reforms in the late 1980s.

Another feature of the medical response to AIDS has been its contribution to the shift in balance between medical and penal approaches to drug misuse. As outlined in Chapter 2, the response to drug misuse in Edinburgh during the early 1980s was characterised by a strong penal approach, particularly in the form of heavy custodial sentences, for those found to be in possession of illicit drugs or equipment. This approach was paralleled by a medical response of scepticism towards harm minimisation measures and reluctance to become directly involved. However, by the end of 1994, the advent of AIDS in Edinburgh had led to a medical approach to drug

misuse that embraced harm minimisation and which extended to other parts of Scotland, and finally included the use of substitute therapy in some Scottish prisons. The Report of the Scottish Drugs Task Force in 1994 also recognised the Edinburgh CDPS model, not only as a means of preventing disease, but also of controlling drug misuse and drug-related crime.

The medical response to AIDS is also part of a larger history of psychiatry in Edinburgh. Psychiatric reluctance to respond to AIDS was due, in part, to anxieties over the correctness of maintenance therapy as treatment for drug misuse. The result of these anxieties contributed to the development of a community-based approach to drug misuse, where much of the prescribing came from GPs, as was the case before psychiatrists were encouraged to take an active role.

Finally, the medical response to AIDS in Edinburgh has also highlighted differences in the structure of the Scottish BTS, one that witnessed an early response with respect to blood donation policy ahead of other parts of the UK. This response forms part of a history of the BTS in Edinburgh, as shown in Chapter 3, where the strong tradition of voluntary blood donation contributed to the move towards self-sufficiency in Scotland.

The Relationship between Voluntarism and the State

A second theme within the Edinburgh response to AIDS has been the role of voluntarism and its relationship with the statutory sector. This thesis has shown, in Chapter 3, that the early work of Scottish AIDS Monitor (SAM) was part of a

collaborative initiative between the Scottish Homosexual Rights Group (SHRG) and the Edinburgh and South East Scotland Blood BTS. SAM maintained its relationship with the BTS and grew in strength with recognition from the SHHD in the form of funding.

In 1986, members of SAM formed the Milestone Trust and attempted to encourage support from the statutory sector in developing an AIDS hospice. In 1987, the relationship between the voluntary and statutory sectors had become closer and this was reflected in the composition of the Regional AIDS Group (RAG), whose membership had been extended to include representations from AIDS voluntary groups, in an effort to ensure closer collaborations, especially with respect to the provision of hospice facilities, as outlined in Chapter 7. These partnerships were also endorsed in the Tayler Report in May 1987.

Chapter 7 also showed that, as relations between the two sectors developed, the potential for conflict over issues of control also developed. The late 1980s was a period when some members of the voluntary sector felt increasingly marginalized. At the same time, new voluntary groups emerged, some with figureheads who were professionalised and had strong connections with the statutory sector. In the early 1990s, the voluntary and statutory sectors underwent a period of restructuring in an attempt to establish better working relations in response to AIDS. However, as was shown, in Chapter 9, some friction persisted over this period.

Despite ongoing tensions, the development of closer relationships between the two sectors provided the framework for future working relationships, which followed

upon further changes in the structure of the health and social services, and the introduction of Community Care, as outlined in the Griffiths Report in 1988. This went some way to define the co-participation of statutory and voluntary services.

The Role of Gender

A third theme identified in this thesis has been the gendered nature of policy. From 1985, with the discovery of HTLV-III amongst drug misusers, women were singled out and became the focus of the early AIDS response in Edinburgh. This was particularly so with respect to the introduction of an antenatal screening programme for those found to be at high risk. Women with a history of drug misuse came to be seen as the vectors of disease. Linked to this was the description of drug misusing female prostitutes as the 'bridging group' between heroin addicts and the unsuspecting general public. In addition, the focus on women also revealed wider anxieties about women's role in society, especially as mothers. Concerns about the burden of responsibility of care for HIV-positive women and their children fed into debates around the need for wider screening measures.

In the late 1980s, screening for HIV was extended to all pregnant women in Edinburgh, as part of a research proposal into the heterosexual spread of disease. As shown in Chapter 7, pregnant women, by virtue of their place of residence, came under medical scrutiny. At the same time, as Chapter 8 indicated, health education campaigns appeared to focus on women, placing the burden to 'Take Care' on them.

By the 1990s, women were simultaneously viewed as the vectors of disease and the innocent victims of disease. As outlined in Chapter 9, health education redressed

some of the gender differences identified in earlier campaigns and subsequent efforts sought to empower women. Feeding into some of the debates over gender inequalities were anxieties that many women were vulnerable and unable to assert themselves when addressing issues of safer sex.

The gendered difference in policy response to AIDS in Edinburgh is also part of the wider history of the social response to disease, which highlights the discriminatory nature of policy, especially at times of perceived crisis. These measures particularly resonate with earlier responses to STDs in Scotland, which revealed the ways in which women were often perceived as the vectors of disease. The history of STDs in Scotland has shown that the testing of antenatal women was carried out because they were frequently seen as easy targets for epidemiological research and public health interests. In this study, it has also been argued that the extension of antenatal screening was part of larger developments in modern medicine, which attempted to medicalize healthy populations.

The Role of the Scottish Media

A fourth theme to emerge in this thesis has been the role of the Scottish media, particularly the press, and its response to AIDS. This study has shown that the relationship between AIDS and the media was complex, yet varied. However, in many ways the route followed by the Scottish media was similar to other interpretations of the UK press. For example, during the period of the early response to AIDS in Edinburgh, 1982-1984, media presentations appeared to be dominated by perceptions of AIDS as a 'gay plague', particularly by the tabloid press, as outlined in

Chapter 3, serving to reinforce homophobia. The presentation of AIDS as a male homosexual disease was also evident within the gay press, as magazines such as *Gay Scotland* adopted the role of informing its community of the dangers of AIDS. By 1984, the Scottish press started to simultaneously present AIDS as a heterosexual disease within the context of concerns about the safety of blood supplies and the knowledge that some haemophiliacs had contracted AIDS. However, as shown in Chapter 4, by the end of 1985, with the discovery of HTLV-III in Edinburgh, the Scottish press increasingly turned its attention to AIDS as a disease associated with drug misusers. A particular focus in the tabloid press was upon female drug misusers as the vectors of disease, through mother-to-child transmission.

During the period 1986-1987, the Scottish press continued to focus on female drug misusers. However, attention moved to concerns about heterosexual transmission and the role of prostitution. Stories of prostitutes with AIDS working in Leith were a feature of the Scottish press during this time, as evident in Chapter 5, contributing to the generation of fear and panic.

Between 1987-1989, the press continued to present AIDS as a disease associated with drug misuse, and further emphasised the threat of heterosexual spread, at a time when the UK media were playing down the threat. By the late 1980s, stories, such as those outlined in Chapter 8, warned that a heterosexual epidemic was about to break out in the City. Similarly, this was followed in 1989 with stories that Edinburgh was facing a new threat from an expanding sex industry, as shown in Chapter 9.

During 1990-1994, the Scottish press continued to present AIDS as a heterosexual disease, unlike their English counterparts. However, new vectors of AIDS were portrayed. These were drug misusing prisoners. As outlined in Chapter 10, stories of Scottish prisoners sharing needles behind bars were presented as a potential threat to the wider public upon their release from prison.

This thesis has also revealed the media's relationship with the policy process. It has been evident throughout the period of this study, that use was made of the press by the policy community to raise awareness of AIDS, in an attempt to attract government attention and stimulate action. An example of this is highlighted in Chapter 6, when the Scottish Office's delay in responding to the issue of needle exchange, as outlined in the McClelland Report, was reported in the media by Brian McClelland. Furthermore, as noted in Chapter 4, in order to prevent panic and alarm, the SHHD were prepared to remain silent when the media gave Scotland a clean bill of health at a time when the incidence of HTLV-III amongst haemophiliacs was known. However, there were also times, as outlined in Chapter 4, when the SHHD felt they had to follow suit with England because there would be media pressure to do so.

Furthermore, this thesis has indicated that the media entered into relations not only with the policy community or civil servants, but also politicians. For example, as Chapter 6 shows, in 1986, the press was used by politicians, such as MacKay, in an attempt to reinforce morality and potentially influence the public.

However, the media simultaneously adopted a sense of responsibility and sensitivity in contributing to health education measures. At the early stages of the response to

AIDS, gay magazines, such as *Gay Scotland*, offered advice and information on the risks of AIDS. This was also the case with the popular press. For example, by the late 1980s, the *Edinburgh Evening News* committed themselves to promoting Lothian's 'Take Care' campaign. By 1992, the Scottish Office was actively encouraging contact between Health Education Agencies and the media in order to promote health education about AIDS. Overall, this thesis has argued that the media has had an influential role on AIDS policy-making in Scotland, and, as other histories of AIDS in the UK have documented, enjoyed a developing inter-relationship with policy-makers which was far from a 'New Right' moral panic response.

The Role of Morality

A final theme that runs throughout the period of AIDS policy-making in Edinburgh has been the ongoing debates over compulsion, with respect to treatment, prevention, screening and contact tracing. These debates have revealed a strong moral agenda operating in Edinburgh, and arguably Scotland. For example, as shown in Chapter 4, at the local level a moral agenda was often conflated with medical and scientific arguments in response to AIDS. Epidemiological concepts of risk groups were, at times, interpreted within a moral framework which distinguished between patients perceived as 'innocent' or 'guilty' of disease or having 'brought it on themselves'. Similarly, while epidemiological evidence was used to uphold the view that a heterosexual epidemic was waiting to happen in Edinburgh, this view was underpinned by a perception of drug misusers as promiscuous, chaotic and immoral.

A strong moral agenda was also evident at all levels of the Scottish Office. MacKay, in particular, stands out as an advocate of a strong moral response to AIDS; one that distinguished between the 'guilty' and the 'innocent'. Many civil servants were also against the introduction of free needles and syringes, not only because of financial and legal implications, but because there was a perception that such a measure was seen to condone an immoral and illegal act. This was evident in Chapter 6, during heated debates over the kind of needle exchange service that ought to be introduced. In the SHHD, there was a strong compulsionist tendency to control drug misuse as well as AIDS. This was reflected in the type of needle exchanges introduced in Scotland which were controlled by the medical profession and limited in times of opening and number of syringes allowed per visit. Similarly, fears about drug misusers fed into debates over screening and contact tracing in the early 1990s. As shown, in Chapter 10, calls for contact tracing, conflicted with arguments that defended the rights of individuals.

An added constraint over the liberal nature of AIDS policy-making was the Scottish legal system. As outlined in Chapters 6 and 9, this was evident during debates around the supply of needles and syringes and the supply of condoms. Although the Lord Advocate, the Procurator Fiscal, and the police in Edinburgh were sympathetic to public health considerations, there remained the possibility that problems could arise in relation to equipment such as needles and condoms being used as circumstantial evidence of drug misuse or soliciting.

Similarly, the views of religious groups in Scotland demonstrated a strong moral ideology, especially with respect to the need for the promotion of chastity within

public health education campaigns. As shown in Chapter 6, while some politicians, such as MacKay, shared the Churches' standpoint, their views were considered to be at odds with the majority of Government, who felt that a pragmatic health education approach, rather than a moral one, was needed to curtail the spread of disease. Nonetheless, as noted in Chapter 8, Scottish churches continued to put pressure upon policy-makers, in an attempt to ensure that pragmatic approaches also included references to the benefits of cutting down on the number of sexual partners.

The moral response to AIDS is also part of a larger picture on the history of the response to STDs in twentieth-century Scotland, one where political debates were often fuelled by conflict between medicalists and moralists.

Coda: Future Areas for Research on the History of the Response to AIDS in Edinburgh

This study has revealed a number of gaps that remain to be investigated by future historians. Firstly, by using Berridge's stadial model as a conceptual framework with which to examine policy changes in response to AIDS between 1981-1994, this thesis has shown that a strong element of the 'Wartime Response' phase continued in Edinburgh up to 1994, amid the ongoing concern that a heterosexual epidemic could occur. What remains to be examined, is when this perception started to wane, and the 'post war' phase became a more prominent feature of the AIDS policy response. Time constraints have prevented me from taking this research one step further to examine when this was achieved. The Freedom of Information (Scotland) Act 2002, which was implemented in 2005, should be able to provide a historian with access to

records beyond 1994, although Data Protection issues may well present ongoing problems.

Second, as mentioned in Chapter 1, time constraints and a forthcoming public inquiry into the infection of patients with hepatitis C and HIV through blood products, led to the decision not to carry out any in-depth interviews or oral histories. However, such a study would complement this thesis, by providing another source of rich qualitative data, which would capture more clearly the voices and narratives of those involved.

Third, a further area, which remains largely unexplored, is an in-depth account of the Scottish Media's response to AIDS in Edinburgh and Scotland. Although this study has uncovered some of the media's response to AIDS in Edinburgh during this period, time constraints prevented a thorough examination which could include a systematic analysis of the press, television and radio to establish the extent to which further differences, if any, emerged between UK presentations and Scottish ones.

Finally, it is hoped that this thesis will furnish the basis of future comparative analysis of the social response to AIDS both with respect to other Scottish cities, and to other urban societies around the world. For it is in furnishing such a perspective that, as John Pickstone and others have rightly acknowledged, the intensive local/regional study can be of most value to the social historian of medicine.

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